REPORT
ON
TESTING FOR AIDS

ONTARIO LAW REFORM COMMISSION

1992

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ONTARIO LAW REFORM COMMISSION

1992

The Ontario Law Reform Commission was established by the Ontario Government in 1964 as an independent legal research institute. It was the first Law Reform Commission to be created in the Commonwealth. It recommends reform in statute law, common law, jurisprudence, judicial and quasi-judicial procedures, and in issues dealing with the administration of justice in Ontario.

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Appendix I

Ontario
Law Reform
Commission

To The Honourable Howard Hampton
Attorney General for Ontario

Dear Attorney:

We have the honour to submit our *Report on Testing for AIDS.*

Rosalie S. Abella
Chair

Richard Simeon

Richard E.B. Simeon
Vice Chair

Earl A. Cherniak
Commissioner

John D. McCamus
Commissioner

Margaret Ross

Margaret A. Ross
Commissioner

March 12, 1992

PREFACE

The Commission's *Report on Testing for AIDS* was initiated as the first report in a series of projects dealing with testing issues. Christine Henderson, a Counsel at the Commission, was primarily responsible for the project.

An Advisory Board was established by the Commission, composed of individuals from various disciplines and organizations. The Commission would like to express its deep appreciation to the members of the Board, who made a significant contribution to this project: Professor Tom Alloway, University of Toronto, Chair, Haemophilia Services (Haemophilia Ontario); Calvin Bernard, Ontario Human Rights Commission; Charles Black, Vice President Insurance Operations, Canadian Life & Health Insurance Association; Ray Brillinger, Canadian Manufacturers' Association; Alan Cornwall, AIDS Action Now!; Jane Darville, Executive Director, Casey House Hospice; Wayne Donald, First Vice President, Metro Toronto Civic Employees Union; Bill Downer, Street Outreach Services; Bill Ekins, Executive Director, Toronto AIDS Drop-In Centre; Dr. Ian Gemmill, Ottawa-Carleton Health Department, Association of Local Official Health Agencies; Beric German, Street Health; David Lillico, Legal Branch, Ministry of Citizenship; Julie Lindhout, Director, Legislation Branch, Ontario Ministry of Education; Frances MacCusworth, Health Care Committee, Ontario Dental Association; Stephen Manning, Executive Director, AIDS Committee of Toronto; Mary Morison, Ontario Federation of Labour; Maureen O'Halloran, Ontario Nurses Association; Dr. Diane Riley, Canadian Centre on Substance Abuse, University of Toronto; Dr. Richard Schabas, Chief Medical Officer of Health for Ontario; Dr. Anthony Shardt, Ontario College of Physicians and Surgeons; Margaret Shaw, Counsellor, Women's Clinic, Hassle Free Clinic; Hillary Short, General Manager of Public Affairs, Ontario Hospital Association; Dr. Margaret Somerville, Director, McGill Centre for Medicine, Ethics & Law; Bill Sparks, Executive Member, Ontario Public School Teachers' Foundation; Dr. Maritza Tennessee, Canadian Centre for Occupational Health and Safety; Robert Trow, Counsellor, Men's Clinic, Hassle Free Clinic; Janice Trudeau, Community Health Worker, AIDS Prevention Program, Anishnawbe Health Toronto; Dr. Evelyn Wallace, Senior Medical Consultant, Ministry of Health; Tom Windebank, Operation Policy, Ministry of Correctional Services; Cezarina Wysocki, Legal Services, Ministry of Health. In addition, the Commission advertised for submissions. The Commission would like to thank the organizations and individuals who responded to the issues discussed in the advertisements.

The Commission would like to express its gratitude to William Flanagan, Assistant Professor at the Faculty of Law, Queen's University, who was an indispensable source of information and research for this report. We also wish to acknowledge the important contribution of Professor Bernard Dickens, of the Faculty of Law, University of Toronto, a consultant to the Commission for this project. Finally, the Commission would like to express its appreciation to Dr. Philip Berger, and to Dr. Alan Meltzer, of the Federal Centre for AIDS, both of whom gave their time and expertise so generously.

INTRODUCTION

Preventing the spread of the human immunodeficiency virus (HIV) is one of the great public health challenges of the 1990s.[1] Policy makers face unique and difficult dilemmas in the formulation of rational public health strategies to reduce the further spread of HIV infection and acquired immune deficiency syndrome (AIDS). The development of public health policy concerning mandatory testing for HIV, a focal point of this report, is particularly problematic.

When AIDS was first identified as a blood-borne infectious disease in 1981,[2] little was known about its etiology. In the relative absence of medical knowledge, a social picture emerged of AIDS as a disease that afflicted only certain groups.[3] In 1983 the causative agent of the disease – the human immunodeficiency virus – was identified, and in 1985 the HIV antibody test was developed.[4] Researchers learned that the disease is not transmitted through casual contact, and that it can be prevented by avoiding specific high-risk behaviour.[5] Nonetheless, the individuals most affected in North America are still homosexual and bisexual men and injection drug users, and HIV infection is still widely perceived as a disease unique to those groups.[6]

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[1] Canada, Health and Welfare, *HIV and AIDS: Canada's Blueprint* (1990), at 6.

[2] The first cases of AIDS were identified in 1981. As of October 7, 1991, more than 5,340 cases were reported in Canada, and over 25,000 Canadians are probably infected with the human immunodeficiency virus (HIV), the cause of AIDS. See *infra*, ch. 1.

[3] The name first given to this new, devastating disease was "G.R.I.D.", that is, "Gay Related Immunodeficiency Disease". See Altman, *AIDS in the Mind of America* (1986), at 33.

[4] The blood test to determine the presence of the HIV antibody is currently the most accurate widely available means to determine whether a person is (1) infected with HIV, (2) is infectious, and (3) will develop any of the serious and life-threatening conditions associated with AIDS. Generally speaking, a person who tests "seropositive" is considered to be infected with HIV, is presumed to remain infectious for life, and is at a very serious risk of developing a related life-threatening condition as the infection progresses. See *infra*, ch. 1.

[5] *Infra*, ch. 1.

[6] In some regions of the world where HIV infection is endemic, such as Central Africa and Haiti, there are very high HIV seroprevalence rates of 5 percent to 15 percent of the total population, or about 100 times higher than in Canada. In these regions, the majority of HIV-infected persons are heterosexual, and HIV is primarily transmitted through heterosexual contact. The use of blood from unscreened donors and the frequent use of injections with unsterilized needles also contributes to the spread of HIV. See Royal Society of Canada, *AIDS: A Perspective for Canadians, (Summary of Report and Recommendations)* (1988), at 4. See, also, de Zalduondo *et al.*, "AIDS in Africa: Diversity in the Global Pandemic" (1988), 118 Daedalus 165.

With the introduction of the HIV antibody test, a host of questions emerged, many of which remain unresolved. How would the test, demonstrably useful in preventing HIV transmission from donated blood, be employed elsewhere? Would groups at risk of infection be encouraged, or perhaps forced, to be tested? What would the consequences of testing be respecting the right to work, bear children, attend school, obtain insurance, or remain free?

In this report we consider these questions in the light of the complex social, medical, and legal contexts from which they emerged. We examine the issues connected with the development of HIV testing policies against the background of our present knowledge to assess the appropriateness, at this time, of involuntary public health measures, including involuntary testing for HIV. The task is especially difficult because of the constantly changing environment as therapeutic interventions and diagnostic tools develop and improve, and the epidemic evolves.[7]

As our knowledge increases, it is almost certain that the response of policy makers and society as a whole to AIDS and HIV infection will change. Rather than relying exclusively on the occasionally inaccurate HIV antibody test, for example, researchers may soon develop tests that can more accurately diagnose HIV infection. As new scientific tools are developed, the HIV antibody test *per se* may become less relevant as it is replaced with new and more accurate markers of infection or disease progression. As therapeutic interventions improve, there will be greater incentive for those who are infected to come forward. But now, in the absence of effective treatment and in the presence of a stigmatizing social understanding of AIDS, the most successful efforts to reduce the spread of infection focus upon the public health strategy of encouraging individuals at risk to determine voluntarily their HIV status and to engage in risk-reducing behaviour. Nonetheless, whatever the advances in scientific technology, the values that govern the development of policies concerning HIV infection—such as the principle of autonomy and respect for persons—will remain constant.

In chapter 1 we focus upon the human immunodeficiency virus and its transmission; following a description of disease progression, HIV-related testing, and the problems associated with testing, we conclude with a discus-

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There is considerable debate about whether this pattern of transmission is likely to be duplicated in the developed countries. To date, in contrast to Africa, there is a comparatively low incidence of the heterosexual transmission of HIV infection in Canada. However, as HIV infection becomes more prevalent, this pattern of infection may change and the incidence of heterosexual transmission may increase.

[7] Washington, D.C., Institute of Health, *HIV Screening of Pregnant Women and Infants*, Hardy (ed.) (1991), at v.

sion concerning treatment. In chapter 2 we examine the criteria that must be satisfied before HIV-related testing may be considered. After defining voluntary, mandatory, and compulsory testing, we discuss the requirements of voluntary, specific, and informed consent. The possible objectives of testing are set out, and an analysis of the relevant legal and medical requirements is applied to the HIV testing of specific populations. A discussion of testing in the workplace in the context of public health and safety follows. The chapter concludes with a section on epidemiological screening.

In chapter 3 we examine Ontario's policies of compulsory nominal reporting and contact tracing. The legal, practical, and social impacts of these measures are considered in the context of two important social interests – the principle of confidentiality and the protection of public health. The report concludes with a summary of the Commission's recommendations.

CHAPTER 1

THE HUMAN IMMUNODEFICIENCY VIRUS

1. BACKGROUND

In this chapter we will consider how Acquired Immune Deficiency Syndrome (AIDS) develops, the transmission of infection, and the projected spread of the disease. We will examine definitions, types, and methods of testing and assess the benefits and risks of testing. The chapter concludes with a discussion about treatment.

In June, 1981, the United States Centers for Disease Control publication *Morbidity and Mortality Weekly Report* (MMWR) reported outbreaks of *pneumocystis carinii* pneumonia (PCP) among five young homosexual men.[1] The two-page report was the first indication in North America of the illness caused by the human immunodeficiency virus (HIV).[2] Unrecognized, the disease had begun its spread worldwide during the 1970s.[3]

In Canada the first case of AIDS was reported in February, 1982.[4] As of October 7, 1991, more than 5,340 cases of AIDS had been reported to the Federal Centre for AIDS.[5] Although it is not known how many persons in Canada are infected with the virus at present, estimates of the number have ranged from 10,000 to 100,000 over the past few years.[6] Projections indicate that by the end of 1993 there will be approximately 7,600 cases of AIDS cumulatively in Canada;[7] it is difficult to estimate the number of persons who will be HIV-infected at that time. AIDS is only the final clinical stage of HIV infection. Persons infected with HIV generally show progressive immunologic deficiency over a period of years. A continuum of conditions results, from initial infection through seroconversion and asymptomatic HIV infection to the most advanced stage, AIDS. This spectrum generally encompasses a great variety of clinical symptoms. In this report we use the term "HIV infection" to refer to the continuum of conditions resulting from infection with HIV.

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[1] "Pneumocystis Pneumonia—Los Angeles" (1981), 30 MMWR 250.

[2] Clayton, "AIDS at the Federal Level—A Personal Reflection" (1989), 80 Can. J. Pub. Health (Supp. 1) S12; Ontario, Ministry of Health, *Understanding AIDS and HIV Infection: Information for Hospitals and Health Professionals* (1988), at 3, *n.* 1 (hereinafter referred to as "*Understanding AIDS and HIV Infection*") states: "The virus was formerly known as human T-cell lymphotropic virus-III (HTLV-III), lymphadenopathy associated virus (LAV), AIDS-associated virus (ARV) and immunodeficiency-associated virus (IDAV). To eliminate the multiplicity of names in use, a sub-committee of the International Committee on Taxonomy of Viruses recommended the new name which conforms to the rules for naming retroviruses in that it begins with the name of the host species and 'denotes a major (though not the only) pathogenic property of the prototypic members of the group.'... Ontario Disease Surveillance Report (ODSR), Volume 7, No. 33, August 15, 1986."

[3] Glenn *et al.*, *HIV Infection, AIDS and Privacy*, working paper (March, 1990), at 9.

[4] Clayton, *supra*, note 2, at 512.

[5] Canada, Federal Centre for AIDS, *Surveillance Update: AIDS in Canada* (October 7, 1991), at 1 (hereinafter referred to as "FCA, *Surveillance Update*").

At present, the principal risk factor for AIDS in Canada in adult males is unsafe homosexual or bisexual activity (82 percent of adult male cases.)[8] Much of what has been learned about the clinical features of AIDS comes from experience with this group.[9] However, heterosexual women now constitute the fastest-growing group of new AIDS cases in Canada.[10] In the United States, AIDS in women is inextricably linked to injection drug use;[11] in Canada, both high-risk behavioural factors and social factors contribute to the spread of infection among women.[12] Commentators generally agree that more epidemiological data are needed to develop strategies for the provision of services that will be required to cope with the disease.[13] The problem of epidemiological surveillance will be examined later.[14]

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[6] Canada, Health and Welfare, *HIV and AIDS: Canada's Blueprint* (1990), at 14 (hereinafter referred to as "*HIV and AIDS: Canada's Blueprint*").

[7] FCA, *Surveillance Update*, *supra*, note 5, at 8 states: "Estimates of the number of new cases of AIDS have been derived using modelling techniques. The logistic model is empirical.... The projections are based on adjusted cases (adjusted for delays between date of diagnosis and date of report) that were diagnosed before October 1, 1988 and reported to the FCA as of March 31, 1989. Backcalculation projections include adjustments for 20% underreporting and for delayed reporting." By 1993, the logistical model puts the projected cumulative cases of AIDS in Canada at 7, 648; the back-calculation cumulative total is 11,374.

[8] FCA, *Surveillance Update*, *supra*, note 5, at 8.

[9] Royal Society of Canada, *AIDS: A Perspective for Canadians* (*Summary of Report and Recommendations*) (1988), at 3.

[10] FCA, *Surveillance Update*, *supra*, note 5.

[11] Washington, D.C., Institute of Medicine, *HIV Screening of Pregnant Women and Newborns*, Hardy (ed.) (1991), at 14 (hereinafter referred to as "*HIV Screening of Pregnant Women and Newborns*").

[12] *HIV and AIDS: Canada's Blueprint*, *supra*, note 6, at 15; Hankins *et al.*, "HIV Infection Among Quebec Women Giving Birth to Live Infants" (1990), 143 Can. Med. A.J. 885, at 890.

Occasionally, the language associated with the AIDS epidemic has caused confusion. For example, the term "AIDS test" is a misnomer because it implies that persons testing positive have AIDS.[15] The test used most often at present does not measure for the presence of AIDS or even HIV: it measures antibodies produced against HIV.[16] We prefer to use the term "HIV antibody test". The term "AIDS virus" is open to challenge, because a positive result does *not*, by itself, indicate that an individual has AIDS. It is likely that most HIV-infected adults will develop some illness five to ten years after becoming infected, and 50 percent will develop AIDS within ten years.[17] The phrase "exposed to the virus" is often used to describe the contracting of HIV infection. This suggests the kind of casual contact associated with being "exposed" to a cold. In this report we refer to persons who have "contracted or acquired the virus." While there is little difference in the dictionary definitions of the words "infectious" and "contagious", it is preferable to use the former when referring to HIV.[18] In popular use the word "contagious" is usually associated with a virus that is transmitted through casual contact. Much of the fear and anxiety surrounding the disease stems from the view that "not enough is known about the virus".[19] However, Health and Welfare Canada and the U.S. Centers for Disease Control state affirmatively that HIV cannot be transmitted through casual contact.[20] Finally, while the discussion focuses on the HIV antibody test as the most commonly used marker of HIV infection, this report and its recommendations are meant to apply to *all* HIV-related tests.[21]

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[13] See, for example, Royal Society of Canada, *supra*, note 9, at 13, 22. See, also, *Understanding AIDS and HIV Infection, supra*, note 2, at 25. With respect to the importance of epidemiological data it states: "The timely collection of accurate data is essential to monitor the disease. It is through sound epidemiological data that researchers and scientists have been able to determine the routes of the disease, and then work to prevent its spread."

[14] See *infra*, ch. 2, sec. 5.

[15] AMA Management Briefing, *AIDS: The New Workplace Issues* (1988), at 10.

[16] This is the enzyme-linked immunosorbent assay, or "ELISA". While the ELISA in combination with the Western Blot Test are the most commonly used markers of an infection, there are a number of others.

[17] Glenn *et al.*, *supra*, note 3, at 14-15. See, also, Grieg, *AIDS: What Every Responsible Canadian Should Know* (1987), at 62; Perkins, "Comment: Prohibiting the Use of the Human Immunodeficiency Virus Antibody Test by Employers and Insurers" (1988), 25 Harv. J. on Legis. 275, at 278, which states: "The NAS [National Academy of Sciences] predicts that at least twenty-five to fifty percent of all infected persons will develop AIDS within five to ten years of infection"; Somerville and Gilmore, *Human Immunodeficiency Virus Antibody Testing in Canada*, report submitted to and approved by the National Advisory Committee on AIDS (January 6, 1988), at 2, state, "continuing surveillance of populations of HIV infected persons suggests that as many as 50% of HIV infected adults may develop a serious or fatal illness due to HIV infection"; Jones and Sheppard, "AIDS and Disability Employment Discrimination in and beyond the Classroom" (1989), 12 Dalhousie L.J. 103, at 106, state at *n.* 11: "By recent World Health Organization estimates, 50% of those infected with HIV are likely to develop AIDS within 10 years of infection (Communication with Federal Centre for AIDS)." But compare Canada, Privacy Commissioner of Canada, *AIDS and the Privacy Act* (1989), at 3, which states: "The most pessimistic view is that, without a cure, all these infected people will eventually develop AIDS and die prematurely." See, also, May, Anderson, and Blower, "The Epidemiology and Transmission Dynamics of HIV-AIDS" (1989), 118 Daedalus 163.

Treatment may help to slow the progression of disease, however: see *infra*, this ch., sec. 5.

2. TRANSMISSION OF HIV INFECTION

HIV is transmitted primarily through blood and semen. More specifically, the known routes of HIV transmission are as follows:[22]

by anal intercourse with an infected person;[23]

by vaginal intercourse with an infected person;[24]

by use of needles and other skin-piercing equipment contaminated with infected blood;

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[18] AMA Management Briefing, *supra*, note 15, at 11.

[19] *Ibid.*, at 12.

[20] *Ibid.*; *HIV and AIDS: Canada's Blueprint*, *supra*, note 6, at 10.

[21] For the purposes of this report, we adopt a broad meaning of "HIV-related tests", from the New York HIV and AIDS Related Information Law, §2780.4, as enacted by L. 1988, c. 584, §2 (McKinney Supp., 1989): "'HIV related test' means any laboratory test or series of tests for any virus, antibody, antigen or etiologic agent whatsoever thought to cause or to indicate the presence of [HIV infection]."

[22] Royal Society of Canada, *supra*, note 9, at 3. See, also, World Health Organization, Global Programme on AIDS, *Statement from the Consultation on AIDS and the Workplace* (June, 1988).

[23] The use of condoms during intercourse appears to substantially reduce the risk of HIV transmission. Spermicide in conjunction with condoms may reduce this risk even more: Glenn *et al.*, *supra*, note 3, at 11-12.

[24] *Ibid.*, at 11. In Canada, the majority of HIV-infection cases result from certain homosexual or bisexual practices. In other parts of the world—for example, Africa and the Caribbean—the majority of cases appear to result from heterosexual practices and perinatal transmission: *HIV and AIDS: Canada's Blueprint*, *supra*, note 6, at 20.

> from an infected mother to her fetus (perinatal transmission), and through breastfeeding;[25]
>
> by transfusion of infected blood or blood products;[26]
>
> by tissue, semen, ova, or organ donations from infected donors.[27]

HIV has *not* been transmitted through air, water, or food, or by the touching of an object handled, touched, or breathed upon by a person with AIDS.[28] Casual everyday contact does not spread the virus. As the Surgeon General of the United States has said:[29]

> Everyday living does not present any risk of infection. You cannot get AIDS from casual social contact. Casual social contact should not be confused with casual sexual contact which is a major cause of the spread of the AIDS virus. Casual social contact such as shaking hands, hugging, social kissing, crying, coughing or sneezing, will not transmit the AIDS virus. Nor had AIDS been contracted from swimming in pools or bathing in hot tubs or from eating in restaurants (even if a restaurant worker has AIDS or carries the AIDS virus). AIDS is not contracted from sharing bed linens, towels, cups, straws, dishes, or any other eating utensils. You cannot get AIDS from toilets, doorknobs, telephones, office machinery, or household furniture. You cannot get AIDS from body massages, masturbation or any non-sexual contact.

Indeed, the virus is relatively fragile and dies quickly outside the body.[30] It is easily killed by a diluted solution (10 percent) of household bleach. A total of 491 family members of 228 AIDS patients were carefully followed up in seven studies. These studies failed to show a single instance of HIV infection among household members who did not have additional exposure through blood or sexual activity.[31]

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[25] While the absolute risk of transmission is unclear, there is evidence of postnatal HIV transmission to infants through breast feeding: see *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 38, *n.* 4.

[26] As of November 1985, the Canadian Red Cross, which supplies all blood and blood products to Canadian hospitals, has routinely tested all blood donations for the HIV antibody. In addition, the Red Cross discourages individuals from donating blood if they are a member of a high-risk group or if they suspect they may be infectious: Ontario Hospital Association, *AIDS/HIV Infection: Guidelines and Information for Hospitals* (July, 1988), at 20 (hereinafter referred to as "OHA Report").

[27] HIV antibody tests also are used to screen donations of tissue, organs, etc. to protect recipients of these products: *ibid.*, at 35. There is no general agreement yet as to the probability of HIV transmission during activities identified as modes of transmission. There is, however, general agreement that AIDS has a much lower infectivity rate than other sexually transmitted diseases and that, in particular, the probability of HIV transmission is lower in vaginal intercourse than anal intercourse: Glenn *et al.*, *supra*, note 3, at 11; see, generally, May, Anderson, and Blower, *supra*, note 17.

[28] Ontario, Ministry of Health, *AIDS and the Workplace*, prepared by the Ontario Public Education Panel in AIDS (OPEPA) (January, 1987).

[29] As quoted in *Re Pacific Airlines Ltd. and Canadian Air Line Flight Attendants Association* (1987), 28 L.A.C. (3d) 291 (Can.), at 309.

[30] Royal Society of Canada, *supra*, note 9, at 3.

3. THE COURSE OF THE DISEASE

AIDS, the final clinical stage of HIV infection, results from complications due to the retrovirus called HIV, which disorders the immune system and leaves the body highly susceptible to life-threatening opportunistic infections.[32] HIV is a blood-borne virus attracted to white blood cells called T4 helper cells, as well as many other human cells.[33] The virus has been isolated from many body fluids of infected persons, including blood, semen, saliva, tears, cerebrospinal fluid, breast milk, amniotic fluid, urine, vaginal/cervical secretions, and bronchoalveolar fluid.[34] Although HIV is theoretically transmissible via these fluids, only blood, semen, and vaginal/cervical fluids have been clearly implicated in HIV transmission.[35]

Generally speaking, HIV antibodies appear in the blood as early as two to three weeks, or as late as six months or more, after a person has been infected with the virus.[36] A person who has detectable antibodies in his blood is said to have "seroconverted", and is then termed "seropositive". Shortly after infection, when the antibody level is too low to be detected, the HIV-infected person cannot be identified using HIV antibody tests. However, during this "window period" the person is still considered to be infectious and capable of passing on the virus, even though an HIV antibody test result at this stage will be seronegative.[37] Once infected, a person is considered infectious for life, even though there is evidence that indicates a seropositive person's ability to infect others may vary throughout the course of HIV infection.[38]

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[31] OHA Report, *supra*, note 26, at 21.

[32] Ontario, Ministry of Health, *AIDS and HIV Infection Psycho-Social Issues: Information for Professionals* (July, 1988), at 1.

[33] AMA Management Briefing, *supra*, note 15, at 115.

[34] Hollander, "Transmission of HIV in Body Fluids", [1989] Mass. Med. Soc'y.

[35] World Health Organization, Global Programme on AIDS, *Progress Report Number 5* (May, 1989), at 4 (hereinafter referred to as "WHO/GPA Report No. 5"). See, also, Friedland and Klein, "Transmission of the Human Immunodeficiency Virus" (1987), 317 New Eng. J. Med. 1125, at 1132. There is also evidence of postnatal HIV transmission to infants through breast feeding. See *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 38, *n*. 4.

[36] Royal Society of Canada, *supra*, note 9, at 3.

[37] *Ibid.*

Many persons remain asymptomatic for years after having contracted the virus. However, some people develop symptoms similar to those of mononucleosis shortly after infection. These can include fever, rash, and lymphadenopathy (swollen lymph glands). Persistent lymphadenopathy may or may not develop. The disease sometimes progresses through a stage characterized by varying combinations of symptoms, including fever, gastrointestinal symptoms, weight loss, and oral thrush.[39]

The term "AIDS" has been carefully defined to standardize the diagnosis, reporting, and surveillance of the disease.[40] While there is still some disagreement as to how many of those who are HIV-infected will go on to develop AIDS, the prognosis is pessimistic.[41]

Although HIV infection generally is accepted as the cause of AIDS, other factors may be involved in determining the susceptibility to infection and disease progression. Suggested co-factors have included social conditions, genetic predisposition, drug abuse, malnutrition, genital ulcers, and infections such as cytomegalovirus, mononucleosis, hepatitis-B virus, syphilis, and mycoplasma.[42] Some of these factors are associated with persons who use drugs or have many sexual partners, and their role in relation to HIV infection is as yet undetermined.[43]

The diagnosis of AIDS is defined by the presence of life-threatening opportunistic infections – for example, *pneumocystis carinii* pneumonia (PCP),

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[38] May, Anderson, Blower, *supra*, note 17, at 170.

[39] *Ibid.*

[40] *Understanding AIDS and HIV Infection*, *supra*, note 2, at 4. Patients who are HIV-infected are not diagnosed as having AIDS until they develop one of the opportunistic infections associated with AIDS, or otherwise meet the criteria set out in the definition set by the U.S. Centers for Disease Control and adopted by the Ministry of Health: *ibid.* The U.S. Centers for Disease Control may soon broaden their definition of AIDS, however, to include "any patient whose blood shows a laboratory count of less than 200 CD4 lymphocyte cells per cubic millimeter", which could nearly double the current number of AIDS cases: see *The New York Times*, "Wider Definition May Swell AIDS Total" November 15, 1991.

[41] *Supra*, note 17.

[42] Duesberg and Ellison, "Is HIV the Cause of AIDS?" (1990), 54 Policy Rev. 70, at 76; Royal Society of Canada, *supra*, note 9, at 2.

[43] Duesberg and Ellison, *supra*, note 42. See, also, Bertolini, Canadian Centre for Occupational Health and Safety, *AIDS: A Summary of the Occupational Health Concern* (2d ed., 1989), at 2. It is important to note, however, that a single act of unprotected sexual intercourse with an infected individual could result in transmission.

Kaposi's sarcoma, wasting syndrome, and primary lymphomas of the brain.[44] Nonetheless, many of those who are identified as having AIDS or other HIV-related illness enjoy periods of relatively good health and are able to work. Persons with AIDS live for varying lengths of time; some who were diagnosed with AIDS five years ago are still living.[45] As physicians improve their early management of HIV infection, survival times increase and the quality of life improves for some patients; in fact, HIV infection is now viewed as a chronic viral infection punctuated by a wide variety of opportunistic diseases.[46]

4. TESTING

(a) DEFINITIONS OF TESTING

Testing programs may be voluntary, mandatory, or compulsory. The National Advisory Committee on AIDS has defined HIV antibody testing in the following terms:[47]

(1) *Voluntary testing* - Testing is done only with the informed consent of the person to be tested (or if the person is incompetent, of his or her parent, legal guardian, or next-of-kin, as required by law), and the testing does not fall within the definitions of mandatory or compulsory testing.

(2) *Mandatory testing* - Testing is either a necessary prerequisite for a person to obtain a specified status, benefit, service or access to a given situation, or is a necessary consequence of being provided with one or more of these.

(3) *Compulsory testing* - Testing is required by law, or policy, and the person has no choice to refuse testing and cannot legally avoid it.

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[44] *Understanding AIDS and HIV Infection*, *supra*, note 2, at 4-7. *HIV and AIDS: Canada's Blueprint*, *supra*, note 6, at 46-47; Ontario Medical Association Task Force on HIV/AIDS, "OMA Clinical Traineeship on HIV Infections", Ont. Med. Rev. (April, 1991), at 25 (hereinafter referred to as "OMA Task Force on HIV/AIDS"). The median survival time varies, but with treatment is generally about two years after the diagnosis of AIDS.

[45] AMA Management Briefing, *supra*, note 15, at 115.

[46] OMA Task Force on HIV/AIDS, *supra*, note 44, at 25. Nonetheless, many individuals have died from complications of AIDS within two years of diagnosis. The opportunistic infections associated with AIDS are caused by agents that normally do not induce illness in healthy persons. It is highly unlikely that a healthy person will contract *pneumocystis carinii* pneumonia or other HIV-related illness from a person with AIDS.

[47] Canada, Health and Welfare, "Human Immunodeficiency Virus Antibody Testing in Canada" (1989), 15 Can. Diseases Wkly. Rep. 37; Somerville and Gilmore, *supra*, note 17, at 22.

These definitions of voluntary, mandatory, and compulsory testing for HIV antibody are relied upon throughout this report.

It is also important to define "routine testing" in relation to HIV antibody tests. For the purposes of this report, "routine testing" means the diagnostic use of the HIV antibody test where it is medically indicated, but *without* the patient's express informed consent.[48]

(b) METHODS OF TESTING

Evidence of HIV can be obtained by culturing the virus from blood, tissues, or bodily fluids. However, the most frequently used medical tests focus upon the detection of antibodies specific for HIV in serum rather than on the detection of the virus itself. Antibodies are proteins produced by the body in response to foreign substances such as viruses, bacteria, or even pollen grains.

The World Health Organization has defined HIV antibody testing as a serologic procedure for HIV antibody (or antigen) in an individual, whether recommended by a health care provider or requested by the individual. Often a distinction is made between the testing of an individual and the screening of populations. Screening has been defined as the systematic application of HIV testing to entire populations, selected target populations, or donors of blood, blood products, cells, tissues, and organs.[49] The concepts of screening and testing can be ambiguous.[50] This report uses "testing" to denote the application of HIV-related tests, whether to selected individuals or to all individuals within a defined population; "screening" is used in relation to tests conducted for research or epidemiological purposes only, as in "epidemiological screening".[51]

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[48] Gilmore and Somerville, *Physicians, Ethics and AIDS*, discussion paper commissioned for the Council on Health Care of the Canadian Medical Association (1989), at 9-10.

[49] Somerville and Gilmore, *supra*, note 17, at 19. See WHO/GPA Report No. 5, *supra*, note 35, at 2.

[50] Screening, for example, is ultimately conducted among individuals, and testing, if practised widely by physicians, can be indistinguishable from screening: *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 19, *n*. 2.

[51] *Infra*, ch. 2, sec. 5.

(c) TYPES OF HIV ANTIBODY TESTS

At present, there are several types of serological tests used to detect HIV antibody. These include the enzyme-linked immunosorbent assay (ELISA), the Western Blot, the radioimmunoprecipitationassay (RIPA), and the immunofluorescent assay (IFA).[52] In this section the most common of these tests are described, and the possibility of and reasons for erroneous test results are considered.

The ELISA technique is most widely used because of its accuracy, low cost, and ease of performance.[53] This method detects serum antibodies that react with HIV. The test is extremely sensitive in identifying the condition tested for. In the case of HIV infection, "sensitivity" refers to the probability that the test will be positive if infection is present. Particularly when testing populations with a low prevalence of infection, however, the ELISA may produce some false positive test results.[54] False positives have occurred, for example, in persons with liver disease, and occasionally in multiparous women.[55] As a result, the Ontario Ministry of Health has standardized procedures requiring two positive ELISA[56] test results and further confirmatory testing before test results are considered positive.

"Specificity" refers to the ability of a test to exclude those who do *not* have the condition. In the case of HIV infection, specificity indicates the probability that the test will be negative if infection is absent. A second positive ELISA will not be considered truly positive until validated by a more specific confirmatory test, such as the RIPA, the IFA, or, more commonly, the Western Blot.[57]

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[52] Volberding, "Direct Testing for HIV Antibodies: Methods", [1989] Mass. Med. Soc'y, at 1. A number of other tests are currently under development. The polymerase chain reaction (PCR), for example, appears particularly promising. See *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 77.

[53] Perkins, *supra*, note 17, at 283.

[54] Turner, "False-Positive Results and HIV Seroprevalence Rates" (1991), 144 Can. Med. A.J. 627; Meyer and Pauker, "Screening for HIV: Can We Afford the False Positive Rate?" (1987), 317 New Eng. J. Med. 238.

[55] Volberding, *supra*, note 52, at 2. "Multiparous" refers to "a woman who has given birth at least two times to an infant, whether alive or dead, weighing 500/grams or more or having an estimated length of gestation of at least 20 weeks": Stedman, *Stedman's Medical Dictionary* (1982), at 894.

[56] In the ELISA method a small amount of the patient's serum is incubated in a plastic dish or with beads that have been coated with disrupted HIV or purified viral antigens. If HIV antibodies are present in the serum, they will adhere to antigens on the plate. After reagents are washed and added, a colour reaction will indicate the presence of HIV antibody in the original serum: Volberding, *supra*, note 52, at 1. Sera that do not produce a reaction in the ELISA are considered negative. Those that do will be considered positive (reactive) only if the reaction is repeated on the blood sample. If the result is positive again, the specimen must be subjected to a more specific assay.

When an ELISA result is reactive, but its confirmatory test is negative, the person being tested is considered HIV seronegative. In low-risk populations the ELISA may yield an increased proportion of false positive results.[58] In the majority of cases, however, confirmatory testing corrects these false positive results. If the results of the confirmatory test are inconclusive, the blood sample may be subjected to further testing, or the patient may be asked to undergo testing periodically until a definite result is obtained. Such testing is usually done at three- to six-month intervals. Until a conclusive result is obtained, the patient is counselled to take precautions to prevent possible transmission of the virus.

Despite some of the problems associated with the current HIV antibody tests, a finding of seropositivity generally means that a person has developed antibodies to HIV and is infected.[59] The condition is irreversible, and high-risk activity can transmit the virus to others. A negative test result indicates only that HIV antibodies were not found at the time of testing. This does not necessarily mean that the person is seronegative; it may be that he or she has not yet developed detectable antibodies. If a false negative test is suspected, the individual should be counselled about risk-producing activities that transmit HIV to others. Further testing may be indicated.

There are particular problems in the diagnosis of HIV infection in newborns. Because all babies are born with passively acquired maternal antibodies, the current HIV antibody tests are unable to distinguish between infected and uninfected infants. Consequently, all infants born to HIV-infected mothers will test seropositive up to about fifteen months of age.[60]

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[57] Western Blot assays are similar to ELISA, but the antigen antibody reaction is carried out in solution rather than on a solid surface. It is then subject to electrophoresis, which permits detection of antibodies directed at HIV antigens: Volberding, *supra*, note 52, at 1.

[58] *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 1, *n*. 1.

[59] There is the rare possibility of a false positive result, and patients testing HIV antibody positive should be advised of this possibility by their physicians: Canadian Medical Association, *Human Immunodeficiency Virus Antibody Testing: Counselling Guidelines* (1990), at 5 (hereinafter referred to as "C.M.A., *HIV Antibody Testing*").

[60] *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 77. Several tests under development—for instance, the polymerase chain reaction (PCR)—may prove useful in diagnosing infants. For the moment, however, the PCR requires further evaluation and is generally regarded as a research rather than a diagnostic tool: *ibid.*

There are benefits and risks associated with HIV-related testing. It is essential that those who undergo such testing understand the purpose and nature of the test, and the extent to which the consequences of testing may prove beneficial or harmful. The beneficial consequences of testing may include the establishing or clarifying of a diagnosis of HIV infection; the provision of appropriate health care and early medical intervention; reassurance for those who are seronegative; motivation to modify behaviour; and the notification of partners who may be at risk.[61] For those who are found to be HIV positive, the harmful consequences of testing are grave social and psychological impacts (including the threat of discrimination in employment, insurance, housing, educational, or travel opportunities); the reporting of seropositivity to governments; and stigmatization and ostracism by friends, family, and others.[62]

(d) PROBLEMS WITH TESTING

As mentioned above, a positive ELISA test is followed with a second ELISA test and then with a Western Blot test. Both tests detect the presence of antibodies to HIV infection. However, because of the "latency" or "window period" – the period between infection with HIV and the presence of detectable HIV antibodies – a false negative test may result because a recently infected person has not yet developed detectable antibodies.[63] The latency period source of false negative test results is considered an important source of test error.[64] In addition, the proportion of infected persons in any population who fail to produce antibodies is not known, but has been estimated to be as high as 5 percent. There is also an unknown proportion of HIV-infected persons who are seronegative because HIV antibodies are complexed with HIV antigens.[65] False negatives occur if the test was improperly administered or performed of if the test was lacking in sensitivity to detect antibodies in everyone. In addition, some persons appear to lose antibodies during the course of their infection, although this is considered rare.[66]

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[61] C.M.A., *HIV Antibody Testing*, *supra*, note 59, at 5.

[62] *Ibid.*; *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 1. In addition, testing persons from low-risk populations is also likely to yield an increased proportion of false positive results.

[63] Field, "Testing for AIDS: Uses and Abuses" (1990), 16 Am. J. L. & Med. 33, at 41.

[64] *Ibid.*

[65] Somerville and Gilmore, *supra*, note 17, at 2.

[66] Privacy Commissioner of Canada, *supra*, note 17, at 6.

Any use of HIV antibody testing must include an analysis of the predictive value of test results.[67] The predictive value of a test reflects false positive and false negative results, and will vary according to the prevalence of the condition in the population being studied.[68] The predictive value of a positive HIV test increases, for example, when there is a *high* prevalence of HIV infection in the test population. Similarly, testing programs are most cost-effective when administered to populations in which there is a high prevalence of the condition tested for.[69] A state-administered HIV antibody testing program in Massachusetts and an Illinois premarital screening program illustrate this point.

Until January, 1987, the Massachusetts HIV antibody testing program was limited to persons considered to be at high risk for HIV infection. The program produced a relatively high rate of positive test results—approximately 10 percent of the test population. Between January and March, 1987, a lower-risk testing population reduced that rate to 5 percent. During the latter half of March, the rate of positive test results dropped to 1 percent of the test population.[70] The cost implications of the Massachusetts testing program are significant. The state found that where there was a 10 percent positive rate in the test population, it cost $1,000 to identify a single HIV-infected person. At 5 percent the cost was $2,000, and at 1 percent the cost was $10,000.[71]

The cost implications in the Illinois premarital screening program are even more dramatic. Couples seeking marriage licences were required to undergo a medical examination that included testing for HIV infection.[72] In the program's first year, 1988, an estimated 159,000 people were tested, 23 of whom were HIV positive.[73] The seropositivity rate for the tested population was estimated at 1 in 7,000, the lowest rate of any tested population in the state. The total capital spending for the testing program in 1988 was estimated at $5.6 million,[74] or $243,000 to identify each positive test result.[75]

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[67] Somerville and Gilmore, *supra*, note 17, at 7.

[68] *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 20. See Tables 1(a) and 1(b) in Appendix I to this Report. The predictive value of a positive test diminishes, for example, with declining prevalence in the population. Thus, the proportion of test results liable to be false positives is likely to increase in a population of low prevalence. The corollary is also true.

[69] Perkins, *supra*, note 17, at 284.

[70] *Ibid.*

[71] *Ibid.*

[72] See Ill. Rev. Stat., ch. 40, §204 (1987).

[73] Field, *supra*, note 63, at 73.

5. TREATMENT

A decade after the first AIDS story made headlines, there is still no effective treatment to halt the progression of HIV infection or render the infected person non-infectious.[76] Though the disease is not curable, many of its symptoms are treatable.[77] In fact, many people living with HIV infection are now living longer, and the illness is increasingly seen as a chronic condition. An increasing number of treatments and drugs aimed at treating HIV infection and its symptoms are becoming available.[78] Undoubtedly the most widely administered drug in use today is AZT.[79]

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[74] *Ibid.* Note that individuals, rather than the state, bear the cost of testing.

[75] *Ibid.*, at *n.* 183, which states: "The Chicago Tribune estimated the cost at $228,000 per positive test result. *Repeal the Premarital AIDS Test Law*, Chicago Tribune, Jan. 6, 1989, at 18, col. 1 (editorial)."

[76] Some scientists are optimistic that new, effective therapies are on the way. See, for example, "Engineered Vaccine Boosts Anti-AIDS Cells", *The Globe and Mail*, Toronto (June 13, 1991) A11, which describes a genetically engineered vaccine that boosts the number of disease-fighting immune cells in infected individuals. The vaccine provides "a glimmer of hope" that scientists might be able to "develop a vaccine which could cure those who have the deadly disease": *ibid.*

[77] Friedland, "Clinical Care in the AIDS Epidemic" (Spring, 1989), Daedalus 59, at 72; Riley, *Metro AIDS Training Manual* (March 2, 1990), 13(12), at 63.

[78] Canada's Committee on HIV Therapies was formed by the National Advisory Committee on AIDS in September, 1988, as a "working group on AIDS drugs". In February, 1989, it became a separate committee, reporting to the Assistant Deputy Minister, Health Protection Branch. It provides advice on matters relating to drugs, vaccines, and biologicals for treatment of HIV infection and HIV-related diseases. There are eighteen members on the Committee, including physicians and scientists from across Canada, representatives of the Canadian Pharmaceutical Manufacturers Association, the Canadian AIDS Society, and Health and Welfare Canada. See McGill Centre for Medicine, Ethics and Law (AIDS Research Program), *Responding to HIV/AIDS in Canada*, by Hamblin *et al.*, Release 1 (1991), para. 2.1(e).

[79] *Clinical Courier*, Vol. 8, No. 5 (April, 1990), at 1. AZT is also known as zidovudine, azidodeoxythymidine, azidothymidine or Retrovir. In October, 1991, the federal health minister announced Canadian approval of another AIDS drug, didanosine (commonly known as DDI). The drug will be useful for those patients who can no longer tolerate AZT: *The Globe and Mail*, Toronto (October 10, 1991) A8. Researchers think the best hope for combating the disease may lie in combining drugs in order to minimize their drawbacks and amplify their strengths. Combination therapies have previously proved successful in the treatment of a variety of bacterial and fungal diseases as well as in cancer treatment. See "Strength in Numbers: Researchers Begin Combining Compounds to Fight AIDS" (1990), 263 Scientific American 20.

AZT helps to inhibit the replication of HIV.[80] Consequently, it is beneficial in the treatment of patients with end-stage AIDS, and with the symptomatology of what was formerly called AIDS-Related Complex, or ARC.[81] Increasingly, it is being used even in the early asymptomatic stages of HIV infection.[82] Although AZT is incapable of eliminating the virus and can produce adverse effects,[83] it slows the spread of HIV throughout the body, and it may also alter the course of HIV-induced neurologic disease.[84] AZT therapy has been associated with longer patient survival and a reduction in the frequency and severity of the opportunistic infections that accompany end-stage AIDS.[85] The U.S. Food and Drug Administration (FDA) approved the use of AZT in 1989.[86] Health and Welfare Canada followed suit in 1990.

As with any medical intervention, the benefits of AZT or other therapy must be weighed against the risks. Deciding when to start treatment, particularly in cases of asymptomatic or mildly symptomatic patients, requires continual monitoring to provide reliable data on the disease's progression.[87] A broad range of testing is a vital part of HIV-related treatment. Tests are used to monitor the immune systems of HIV-infected patients and to measure the body's response to treatment. Monitoring tests may also detect signs of early infections and HIV-related malignancies. The frequency of periodic monitoring intervals may vary; generally, intervals of three to six months are recommended.[88]

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[80] Johnson and Hirsch, "New Developments in Antiretroviral Drug Therapy for Human Immunodeficiency Virus Infections" in Volberding and Jacobson (eds.), *AIDS Clinical Review 1990* (1990), 235, at 237.

[81] Since we now see HIV infection as a progression from initial infection to end-stage AIDS as described above, many of the terms formerly used for the various symptoms of HIV infection have fallen into disuse. See Fischl *et al.*, "Prolonged Zidovudine Therapy in Patients with AIDS and Advanced AIDS-Related Complex" (1989), 262 J.A.M.A. 2405.

[82] *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 37. The use of AZT in the early asymptomatic stages of HIV infection provided the basis, in part, for the use of the drug in post-exposure occupational prophylaxis. Occupational exposure to HIV occurs primarily through contact with contaminated blood, by needle-stick injury, or splashes to the mucous membranes of a worker. Some workplaces offer AZT prophylaxis to employees who report occupational exposure within twenty-four hours after the accident. However, considerable doubt has been cast on the theory that a treatment like AZT prophylaxis may have benefits in slowing or preventing infection. As a result, there is no treatment available that has demonstrated safety and efficacy in preventing infection immediately after exposure. The U.S. public health service has declined to make a recommendation concerning the management of post-exposure treatment.

[83] AZT may cause anemia, nausea, and the suppression of the body's own disease-fighting cells. The drug causes fewer adverse effects at lower dosages. Another concern involves the possibility of resistance, which has serious implications because it is directly linked to the question when to begin treatment with AZT.

[84] Friedland, *supra*, note 77, at 73.

[85] United States, Centers for Disease Control, "Public Health Service Statement on Management of Occupational Exposure to Human Immunodeficiency Virus, Including Considerations Regarding Zidovudine Postexposure Use" (1990), 39 MMWR 1, at 3 (hereinafter referred to as "Public Health Service Statement"); Pepe and Molavi, "Zidovudine for the Treatment of HIV Infection" (1990), 42 Am. Fam. Physician Clinical Pharmacology 437; Fischl *et al.*, "The Efficacy of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex" (1987), 317 New Eng. J. Med. 185.

[86] Public Health Service Statement, *supra*, note 85.

A detailed examination of HIV-related testing and treatment is beyond the scope of this section. However, some of the other primary care procedures in the treatment of people living with HIV infection are outlined below. These include the complete cell count for HIV-related anemia and similar diseases. Studies show a strong association between abnormalities discovered through this procedure and disease progression. Other procedures used in caring for HIV-infected patients include chest X-rays, urinalysis, and tuberculin screening, as well as blood tests that may indicate the presence of HIV-related renal disease. Testing for and management of syphilis or other sexually transmitted diseases may be indicated. As well, a hepatitis-B virus (HBV) vaccination may be administered to patients who do not have past exposure to HBV.[89] Vaccinations for influenza and pneumococcus and the use of aerosolized pentamidine or oral medication as a prophylaxis for PCP are also important treatment measures.

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[87] Hecht, Jewett, and Bateman, "Management of HIV Infection in the Seropositive, Asymptomatic Patient", in Holmes *et al.*, *AIDS DX/RX* (1990), 92, at 97-98. AZT therapy is recommended for those adults diagnosed with HIV infection who are asymptomatic, or mildly symptomatic with less than 500 CD4+ lymphocytes. As the disease progresses in HIV-infected individuals, CD4+ lymphocytes generally decline, indicating an increased risk of opportunistic infection. In addition to the drug's prophylactic properties in the treatment of asymptomatic HIV infection, earlier administration results in fewer adverse effects. However, there is inconclusive evidence as to the safety and efficacy of AZT therapy in the treatment of asymptomatic HIV infection, especially where the CD4+ cell count is over 500. In such cases resistance may be of particular concern. While some HIV-infected asymptomatic patients treated with AZT appear to enjoy stronger immunological health, the benefits of early medical intervention must be weighed against the risks in every case.

[88] *Ibid.*, at 96. There are a number of monitoring tests in use. The T-helper lymphocyte (CD4+ cell) count procedure may be the most studied marker of disease progression. Typically, CD4+ cell counts decline as HIV disease progresses, in children as well as in adults. Among HIV-infected adults, a CD4+ cell count of less than 200 is highly predictive of increased risk of *pneumocystis carinii* pneumonia (PCP): United States, Centers for Disease Control, "Guidelines for Prophylaxis Against *Pneumocystis Carinii* Pneumonia for Persons Infected With Human Immunoeficiency Virus" (1989), 38 MMWR 1. Generally speaking, when CD4+ levels are at 500 or less in adults, decisions are made concerning the commencement of drug therapy: *ibid.* Another monitoring test involves a protein called beta-2 microglobulin. Studies show that increased levels of beta-2 microglobulin are correlated with an increased risk of disease progression. While the test is generally available and relatively inexpensive, the CD4+ cell count is a better marker of disease progression. Another component of HIV used as a marker of viral replication is p24 antigen; however, the p24 antigen assay is not a particularly sensitive marker. The antigen, a core protein of the virus, has long been used as an indicator of likely disease progression: *ibid.*; *Treatment News*, National AIDS Bulletin (March, 1991), at 9-10. Further research may develop new and more accurate markers. For now, the researchers at the U.S. National Institute of Health who reviewed the results of a four-year study suggest that the best means of monitoring HIV-infected patients is a combination of tests, which may include CD4+ counts, p24 antigen, and beta-2 microglobulin levels.

No treatment prevents perinatal transmission.[90] However, some medical interventions have been developed for symptomatic HIV-infected children, including drug therapy and prophylaxis for certain opportunistic infections. Some of these measures also may prove effective in treating asymptomatic newborns.[91]

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[89] Hecht, Jewett and Bateman, *supra*, note 87, at 99-102.

[90] Perinatal transmission occurs in about 30 percent of babies born to HIV-infected women: Institute of Health, *HIV Screening of Pregnant Women and Newborns*, *supra*, note 11, at 27.

[91] United States, Centers for Disease Control, "Guidelines for Prophylaxis against *Pneumocystis Carinii* Pneumonia for Children Infected with Human Immunodeficiency Virus" (1991), 40 MMWR 1.

CHAPTER 2

IDENTIFICATION AND AIDS: TESTING FOR HIV INFECTION

1. HIV-RELATED TESTING: THE PROCESS OF IDENTIFICATION

Since the advent of the germ theory, the process of identification has played a prominent role in what might be called the classical biomedical model of infectious disease control. On the one hand, the process of identification—that is, the ability to identify persons with a specific disease—enabled public health officials to target their treatment efforts and preventive measures with the ultimate aim of eliminating further transmission and ending the epidemic. On the other hand, identification carries social costs and risks, both of which are evident in the context of a disease around which a social perception of stigma and shame has been constructed. Therefore the objective of any identification program must, at a minimum, be of sufficient importance to justify its potentially negative social consequences. In short, identification *prima facie* requires a carefully articulated rationale.

Human immunodeficiency virus (HIV)-related identification can take place in a variety of ways. The most common and readily available means of determining HIV infection is the HIV antibody test. Other markers of infection or disease are also available, such as the T4 cell blood test, which is used to assess the degree to which a person may be suffering from some form of HIV-related immunodeficiency. (These topics are discussed in chapter 1 of this report.) As new scientific tools are developed, the current HIV-related tests are likely to be replaced with new and more accurate markers of infection or disease progression. Although this chapter focuses on the HIV antibody test, the discussion is relevant to the collection of any HIV-related information that might be useful in identifying persons who are likely to be infected by means of one of the tests that are available now or that may be developed in the future.

Many arguments have been advanced in favour of some form of HIV-related identification. Among the most important is the protection of the public health, a particularly significant objective with respect to an infectious and fatal illness. However, a number of other objectives are possible. Identification can be used solely for the purposes of individual diagnosis and treatment, an increasingly important factor in the medical management of HIV infection.[1] Economic objectives are possible, as in the case of insurance companies or employers who wish to avoid the costs associated with long-term illness or death. Finally, given the social construction of the disease, thinly veiled discriminatory objectives are also possible, such as the desire of some employers to exclude from their ranks persons who might be HIV-infected. In this chapter we will explore the complex question of the legitimate role of identification in response to this epidemic.

(a) VOLUNTARY, MANDATORY, AND COMPULSORY IDENTIFICATION: SOME DEFINITIONS

Given the serious consequences of one's being identified as HIV-infected, the non-voluntary identification of HIV-infected persons raises issues of particular concern. For this reason, we will focus primarily on the process of non-voluntary identification – that is, mandatory and/or compulsory HIV-related testing. These terms are used and interpreted in a variety of different ways, and it is important to define them again.[2]

A *voluntary* test is performed only with the consent of the person to be tested – that is, where a person is competent, is informed of the consequences, risks, and benefits of undergoing HIV antibody testing, and voluntarily agrees to be tested.[3] In contrast, a *mandatory* test is "either a necessary prerequisite for a person to obtain a specified status, benefit, service or access to a given situation, or is a necessary consequence of being provided with one or more of these".[4] Mandatory HIV antibody testing may be required, for example, of a person who wants to purchase a life insurance policy or donate blood for the purpose of transfusion.[5] Unless the person consents to the test, he or she will be denied life insurance or barred from donating blood. A *compulsory* test is one "required by law, or policy, and the person has no choice to refuse testing and cannot legally avoid it".[6]

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[1] If a treatment is eventually developed that can effectively reduce infectivity, it may also further an important public health objective. See *infra*, this ch., sec. 2(a).

[2] *Supra*, ch. 1, sec. 4(a).

[3] *Infra*, this ch., sec. 1(b).

[4] Canada, Health and Welfare, "Human Immunodeficiency Virus Antibody Testing in Canada" (1989), 15 Can. Diseases Wkly. R. 37, at 37 (hereinafter referred to as "HIV Antibody Testing in Canada".

[5] See *infra*, this ch., sec. 2(a) and 2(g). The mandatory testing of blood donors, for example, can be justified because it is a highly effective means to reduce the spread of HIV and imposes comparatively few costs on donors.

(b) VOLUNTARY HIV-RELATED TESTING: CONSENT TO TREATMENT

Although we will consider some of the many circumstances where mandatory and/or compulsory HIV antibody testing has been proposed, it will be useful to examine first the minimum conditions necessary to meet the legal and ethical requirements for voluntary HIV testing. This discussion is rooted in the doctrine of consent to medical treatment.

The law of consent to medical treatment is continually evolving.[7]

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[6] "HIV Antibody Testing in Canada", *supra*, note 4. Compulsory HIV antibody testing could be required, for example, of prison inmates, who probably would be unable to refuse. Both mandatory and compulsory tests involve an element of coercion, either indirect (through the denial of some status or benefit if the test is refused) or direct (as in the case of compulsory testing, which cannot legally be refused). A voluntary test, by contrast, is free of any element of coercion; the decision to be tested is a voluntary and informed decision ultimately made solely by the patient.

[7] See, generally, Sharpe, *The Law and Medicine in Canada* (2d ed., 1987), at 29-93; and Rozovsky and Rozovsky, *The Canadian Law of Consent to Treatment* (1990), at 1-18.

See, for example, *An Act respecting Consent to Treatment*, Bill 109, 1991 (35 Leg. Ont., 1st Sess.) which codifies the current common law requirements for consent to treatment:

> 4. No health practitioner shall administer treatment to a person unless,
>
> (a) he or she is of the opinion that the person is capable with respect to the treatment, and the person has given consent; or
>
> (b) he or she is of the opinion that the person is incapable with respect to the treatment, and another person has given consent in accordance with this Act.
>
> 5.-(1) The following are the elements required for consent to treatment:
>
> 1. The consent must relate to the particular treatment.
> 2. The consent must be informed.
> 3. The consent must be given voluntarily.
>
> (2) A consent is informed if the person, before giving it, received all the information about the treatment, alternative courses of action and the material effects, risks and side effects in each case that a reasonable person in the same circumstances would require in order to make a decision.
>
> (3) Consent to treatment may be express or implied.

Although the application of this area of the law raises many unresolved questions, of particular concern here is the question whether a physician must obtain a patient's specific informed consent before an HIV-related test can be legally administered, or whether a physician can rely upon a patient's implied or tacit consent to perform an HIV-related test, so long as the patient provides the general consent necessary to obtain a blood sample for diagnostic purposes. There are reports of physicians and hospitals in Ontario having performed HIV antibody tests without obtaining specific informed consent, relying instead on the implied consent to treatment and blood tests that hospital patients typically provide.[8] This is often called "routine" HIV antibody testing – that is, testing without the specific informed consent of the patient.

Consent may be expressly given or merely implied, and it may be either oral or written.[9] Further, *informed* consent is only one of the four compo-

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(4) If there is a prescribed form that applies to the treatment or to the circumstances, the form shall, if possible, be used.

(5) A consent that has been given may be withdrawn at any time,

(a) by the person, if he or she is capable with respect to the treatment;

(b) by the person who is entitled to give or refuse consent on the person's behalf, if he or she is incapable with respect to the treatment.

[8] Barnes, "Doctors Doing AIDS Tests without Consent, CBC Reports" *The Toronto Star* (November 20, 1990). In a recent decision, the Ontario Court of Appeal in *Fleming v. Reid* (1991), 4 O.R. (3d) 74, set out some of the common law principles applicable to doctor-patient relationships, at 85: "The right to determine what shall, or shall not, be done with one's own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlies the doctrine of informed consent. With very limited exceptions, every person's body is considered inviolate, and, accordingly, every competent adult has the right to be free from unwanted medical treatment. The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination. The doctrine of informed consent ensures the freedom of individuals to make choices about their medical care. It is the patient, not the doctor, who ultimately must decide if treatment – any treatment – is to be administered."

[9] Originally, consent to medical treatment was obtained by physicians primarily as a defence against allegations of assault or battery. The tort of battery protects persons from intentional and unpermitted bodily contact. In the absence of consent, any medical treatment that involves actual contact may in some cases give rise to an action in battery. The law, however, recognizes a number of situations in which the obtaining of consent is either impractical or impossible, or not really to the benefit of the patient. In such exceptions, the physician may be relieved of the obligation to obtain the patient's consent. This may be the case in the event of a medico-legal emergency, such as a life- or health-threatening situation requiring immediate treatment where the patient cannot, for some reason, take part in the consent process. See, generally, Rozovsky and Rozovsky, *supra*, note 7, at 19-27.

In addition to liability in battery, any physician who fails to adequately inform a patient of the risks attendant on the treatment in question may also be found liable in nents necessary to constitute valid consent to medical treatment:[10]

- the patient must have the mental capacity to give consent;
- the consent must be voluntarily given;
- the consent must be informed; and
- the consent must be directed towards or related to a specific act or set of acts.

Patients have the requisite mental capacity to give consent if they can appreciate the nature and consequences of the proposed treatment and render an informed judgment on that basis.[11] Most important, patients have the right to make an "unreasonable" decision provided that they have the capacity to make a "reasoned" decision. The consent must be voluntary[12] as well as informed. The nature and the purpose of the proposed treatment, as well as the significant risks and benefits, must be disclosed. The patient must be apprised, for example, of "material and special risks" related to the treatment that might influence a reasonable person in the patient's position.[13] Although there is considerable debate about what might constitute a material or special risk in any given treatment in certain circumstances, a risk factor as small as 1 percent or less has been held to be a relevant material risk.[14] In addition, the physician must identify important factors or special circumstances unique to the patient that might affect the patient's decision to consent to the treatment, and must discuss any

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negligence, even if the treatment itself was performed without negligence: see *Reibl v. Hughes*, [1980] 2 S.C.R. 880, 114 D.L.R. (3d) 1 (subsequent references are to 114 D.L.R.). As a result, not only must a physician obtain the general consent necessary to defend against any allegation of battery, but the information given to the patient must be sufficient to defend against any allegation of negligence. In short, a physician may obtain the consent necessary to defend against an action in battery, but if she fails to provide adequate information about the treatment, she may nonetheless be liable in negligence.

[10] Sharpe, *supra*, note 7, at 30.

[11] If the patient is incompetent and no person is legally authorized to consent on the patient's behalf, consent would not be required in the event of a life- or health-threatening situation requiring immediate medical treatment. See Sharpe, *ibid.*

[12] The access to any service or benefit should not depend on one's consenting to an HIV-related test. Such testing would constitute mandatory, not voluntary, testing. In addition, the consent cannot be obtained through any type of coercion or intimidation.

[13] *Reibl v. Hughes, supra*, note 9, at 16.

[14] See *Rayner v. Knickle* (1988), 72 Nfld. & P.E.I.R., 47 C.C.L.T. 141 (P.E.I.T.D.), where the Court held a physician liable for failure to disclose to his patient a 1 percent risk of serious injury from performing an amniocentesis to determine lung maturity in her 35-week fetus.

alternative forms of treatment.[15] Finally, the consent must be directed towards a specific act. Consent to one type of surgery does not authorize the surgeon to perform a different operation or to extend the original procedure, except in an emergency.[16]

For many reasons HIV-related testing is easily distinguished from most standard blood tests. Of prime importance is the fact that the personal, social, and financial consequences of being identified as HIV-infected can be severe.[17] As a result, HIV-related testing only with the voluntary, specific, and informed consent of the patient has been widely endorsed by commentators and public health officials.[18]

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[15] These factors may include not only the risk to the patient's health in the proposed treatment or intervention, but also the personal, financial, or social circumstances of the proposed intervention that might affect the patient. In *Reibl v. Hughes*, *supra*, note 9, at 35, the Court held that because the patient was within only 1½ years of earning pension benefits if he continued to work, a reasonable person would have refused consent for the treatment in question, given the risk of injury as a result of the treatment and the uncertain benefit.

[16] See, for example, *Marshall v. Curry*, [1933] 3 D.L.R. 260, 60 C.C.C. 136 (N.S.S.C.) where the plaintiff underwent surgery for a hernia and awoke from the operation missing one testicle. Although the testicle was diseased, the Court was unwilling to find implied consent to the extended procedure.

[17] Discrimination against HIV-infected persons in the family, in the workplace, and in schools and health care settings remains disturbingly common: Canada, Health and Welfare, *HIV and AIDS: Canada's Blueprint* (1990), at 10 (hereinafter referred to as "*HIV and AIDS: Canada's Blueprint*"). An HIV-positive person must also address the emotional consequences of being infected with an incurable, debilitating, and eventually fatal disease. See, for example, Ontario, Ministry of Health, *AIDS and HIV Infection: Psycho-Social Issues: Information for Professionals* (1988), at 6, which finds that the "stress of [HIV infection] may lead to overwhelming anxiety. The individual may have trouble maintaining emotional equilibrium and be angry and hostile toward loved ones and health care workers. Some individuals...react by withdrawing, becoming depressed or suicidal".

[18] See, for example, Somerville and Gilmore, *Human Immunodeficiency Virus Antibody Testing in Canada*, report submitted to and approved by the National Advisory Committee on AIDS (January 6, 1988), at 25, where the authors state that, as a general principle, "HIV antibody testing should only be done when voluntary, that is with informed consent, and when counselling and education before and following testing are available and offered, and when confidentiality of results or anonymity of testing can be guaranteed".

See, also, Gilmore and Somerville, *Physicians, Ethics and AIDS*, discussion paper commissioned for the Council on Health Care of the Canadian Medical Association (1989), at 8, where the authors state: "As a general principle, HIV antibody testing should be voluntary. Some exceptions are justified, for example, mandatory testing is essential and clearly justified for persons donating blood for transfusion, tissues (including sperm) or organs for transplantation. Compulsory testing is unjustified."

See, also, Canadian Medical Association, *Touching Certain Questions Concerning: The Matter of HIV Testing*, submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (April, 1991), at 6, where the Canadian Medical Association (CMA) states that HIV antibody testing "should be carried out only on the basis of an

As treatment options improve, it will become increasingly common for persons at risk to consent voluntarily to an examination to determine their HIV status.[19] To consider treatment options, however, persons at risk must first determine their HIV status. There is now a wide consensus among public health officials and medical practitioners that everything should be done to encourage the process of *voluntary* identification.[20]

(c) CONSENT TO HIV-RELATED TESTING: AN OPTION FOR LEGISLATIVE REFORM

Recognizing the sensitivity of HIV-related information, the potential for the misuse of that information, and the need to enforce effectively the recognized right of patients to consent to medical treatment, many jurisdictions, particularly in the United States, have enacted HIV-specific legislation that requires as a general rule voluntary, specific, and informed consent for all HIV-related testing.[21] The California and New York legislation is typical. In 1985, shortly after the HIV antibody test was licensed, California was the first state to pass legislation requiring written informed

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explicit or an entailed but in any case competent consent that is given on the basis of appropriately presented and adequately understood information".

See, also, Washington, D.C., Institute of Medicine, *Confronting AIDS: Directions for Public Health, Health Care, and Research* (1986), at 129, where the Institute of Medicine of the National Academy of Sciences recommends that the "decision of whether or not to be tested for antibody to HIV should remain a matter for individual discretion, given the array of potential risks and benefits that the test poses for those tested. Testing should be encouraged in light of its potential public health benefits. Mandatory screening of at-risk individuals is not an ethically acceptable means for attempting to reduce the transmission of infection. In addition, such a mandatory program would not be feasible in an open society". See, also, Washington, D.C., Institute of Medicine, *Confronting AIDS: Update 1988* (1988), at 74 (hereinafter referred to as "*Confronting AIDS: Update 1988*"), where the Academy again recommends "expanded voluntary testing combined with counseling of all those whose behaviour may have put them at risk for exposure to HIV". The Academy concludes, at 72, that "at this time, the only mandatory screening appropriate for public health purposes involves blood, tissue, and organ donation".

[19] See Kegeles *et al.*, "Many People Who Seek Anonymous HIV-Antibody Testing Would Avoid It under Other Circumstances" (1990), 4 AIDS 585.

[20] Consistent with the Ministry of Health's new policy on HIV testing, the provision of anonymous and/or non-nominal HIV antibody tests is a vital component of any program designed to encourage voluntary HIV tests. See *infra*, ch. 3.

[21] California, Colorado, Hawaii, Illinois, Maine, Massachusetts, New York, North Carolina, Oregon, Rhode Island, and Wisconsin all have enacted legislation that requires voluntary, specific, and informed consent before an HIV antibody test can be performed. See George Washington University, *Intergovernmental Health Policy Project: A Synopsis of State AIDS Legislation Enacted during the 1983-87 Legislative Sessions* (1988), at 41-45.

consent for an HIV antibody test.[22] In 1988 New York passed similar legislation requiring specific, written, informed consent for all HIV-related testing.[23] The New York legislation provides a comprehensive definition of informed consent: there must be at a minimum (1) an explanation of the test, including its purpose, the meaning of its results, the benefits of early diagnosis and medical treatment, and the potential for discrimination; (2) an explanation that the test is voluntary and that anonymous testing is available; and (3) an explanation of the confidentiality provisions in effect, including the persons to whom the results may be disclosed.[24]

In Ontario, the *Health Protection and Promotion Act* (HPPA)[25] provides a general legislative scheme governing the rights and obligations of medical officers of health with respect to the identification and control of communicable diseases. Questions of considerable importance are specifically delegated to the Minister of Health, such as the power to issue regulations specifying a disease as communicable, reportable, or virulent for the purposes of the HPPA.[26] The HPPA is silent on when disclosure of HIV-related information may be justified if the legislation simply permits the disclosure of any information collected under the Act "where the disclosure is made for the purposes of public health administration".[27] The medical officer of health thus has wide discretion to release the information whenever he or she deems it appropriate.[28] Public health law in Ontario relies heavily upon administrative prescription and discretion.

However, the current regime of public health law and practice does not ensure that HIV testing is performed only with the voluntary, specific, and informed consent of the patient. Specific additional measures are necessary if conditions requiring the voluntary, specific, and informed consent of patients prior to HIV-related testing are to be consistently met and enforced across the province.

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[22] California Health and Safety Code, §199.22, as en. by Stats. 1985, c. 22, §1; am. by Stats. 1987, c. 1391, §2; Stats. 1988, c. 1581, §5; Stats. 1988, c. 1582, §2 (West Supp. 1990).

[23] New York HIV and AIDS Related Information Law, §2781 (McKinney Supp. 1989) (hereinafter referred to as the "New York Act"). The legislation provides that the consent shall be in writing; however, if a person requests an anonymous test, this person shall be provided with the opportunity to provide written, informed consent through the use of a coded system with no linking of individual identity to the test request or results (§2781.4).

[24] *Ibid.*, §2481.2.

[25] R.S.O. 1980, c. H.7 (hereinafter referred to as "HPPA").

[26] HPPA, s. 97.

[27] HPPA, s. 39(2).

[28] This contrasts sharply with, for example, the New York Act, §2782, which specifies the circumstances where disclosure of HIV-related information is permitted. Generally speaking, disclosure is permitted where required by law or where necessary in order to provide proper medical treatment. Disclosure by the physician is also permitted where it is medically appropriate, where there is a significant risk of infection to a contact, and where the patient refuses to inform the contact.

Legislative or regulatory options are available. The Minister of Health could consider issuing regulations under the HPPA,[29] the *Health Disciplines Act*,[30] or the *Public Hospitals Act*[31] with the objective of governing the circumstances in which an HIV-related test could be performed, including any requirement for specific informed consent. A regulatory approach would avoid the potential inflexibility of legislation and might quell any concern that a legislative precedent was being set for the differential treatment of HIV infection. Of course, under a combination of legislation and regulation, this differential treatment already exists in Ontario.[32] Legislative measures are also possible, as is the case in California and New York. The New York legislation deals effectively and comprehensively with a broad range of issues including, as noted, rules requiring the voluntary, specific, and informed consent of patients before an HIV-related test is conducted,[33] and the circumstances in which mandatory and/or compulsory testing might be permitted,[34] the protection of the confidentiality of HIV-related information, and the disclosure of that information where it is warranted.[35] The New York legislation also contains appropriate enforcement provisions dealing with remedies for violation of its rules respecting the performance of HIV-related tests and the confidentiality of HIV-related information.[36]

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[29] For example, Cabinet enjoys the authority under s. 96(4)(*a*) of the HPPA to issue regulations governing the establishment and operation of clinics for the examination and treatment of sexually transmitted diseases.

[30] R.S.O. 1990, c. H.4. Under Part III, s. 50(*g*) (which regulates the practice of medicine in the province), the Council of the College, with the approval of Cabinet, may generally make regulations "governing standards of practice for the profession". A regulation, for example, could be issued governing specific, informed consent for HIV testing and could likewise be enforced under the discipline proceeding available under ss. 59-61, which provide the Discipline Committee with, among other things, the power to revoke or suspend the licence of a member of the College of Physicians and Surgeons of Ontario who is found guilty of professional misconduct.

[31] R.S.O. 1990, c. P.40. For example, s. 25(2) of O.Reg. 518/88, issued under s. 32(*q*) of the Act, states that where an attending physician requires a consent in writing for a diagnostic test, the consent must be signed by the patient or other individual as set out in the section. The section does not specify any of the diagnostic tests for which consent is necessary; only if a physician believes consent in writing is necessary does the regulation come into effect. A further provision could be added to the regulations (issued pursuant to s. 32(*q*)) that would require consent for an HIV test. This would ensure that HIV testing in the hospital setting, the site where testing without consent is most common, is performed only with appropriate consent.

[32] For example, AIDS/HIV infection was designated "reportable" and "communicable" under O.Regs. 162/84 and 161/84 issued under the HPPA, which means that HIV infection is already effectively governed by a specific legislative scheme.

[33] New York Act, §2781.

[34] *Ibid.*, §2781.6.

In the Commission's view, the enactment of a comprehensive, HIV-specific statute governing HIV-related testing and the protection of HIV-related information is desirable in Ontario. The Commission recommends that the statute should provide that no HIV-related test should be performed without first receiving the voluntary, specific, and informed consent of the patient, subject only to the exceptions discussed in sections 3(a), (Donors of Blood Products or Bodily Tissues) and 5, (Epidemiological Screening) of this chapter.

2. HIV-RELATED TESTING: OBJECTIVES

(a) Public Health and Infection Control

Identification is a central element in what has been called the classical biomedical model of infectious disease control.[37] Ever since the development of the germ theory, the importance of identifying infected persons to implement public health measures and prevent further infection has played a crucial role.[38] Mandatory testing theoretically permits the identification, treatment, and, if necessary, isolation of all infected persons, and the prevention of further infection outside this group.

(i) Biomedical Model of Infectious Disease Control

It is essential to examine the classical biomedical model of infectious disease control in order to outline an appropriate role for mandatory identification. The classical model typically begins with the discovery of the infectious pathogen and its means of transmission, and is followed by the development of the technology necessary to identify and treat infected individuals. Some form of general "testing" program is usually devised, and is usually accompanied by public health measures requiring physicians to report the names of persons they suspect or know are infected. Public health authorities then institute a follow-up program of infection "control" that focuses almost exclusively on those persons, with the objective of interrupting or eliminating any or all of the possible routes or means of further transmission. In theory, the epidemic is thus contained and eventually brought to an end.[39]

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[35] *Ibid.*, §2782.

[36] *Ibid.*, §2783.

[37] See, for example, Cassel, *The Secret Plague: Venereal Disease in Canada, 1838-1939* (1987), and Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880* (2d ed., 1987).

See, also, Valdiserri, *Preventing AIDS: The Design of Effective Programs* (1989), at 24-29.

[38] This explains why testing, including even the mandatory testing of an entire population, has some appeal as a "firm" response to a devastating infectious disease.

The identification of an infected person can lead to the identification of third parties, called "contacts," who may have been rendered infectious as a result of some interaction with the identified person. "Contact tracing" or "partner notification" can result in the further identification of infected persons, who in turn are subject to the same follow-up program of infection control.

The primary importance of identification in this biomedical model is reflected in almost all modern public health legislation, of which the Ontario HPPA is a typical example: the legislation gives public health officials a wide discretion to require the identification, treatment, and/or isolation of persons with specified infectious diseases, including HIV infection.

Notwithstanding the historical and legislative predominance of the biomedical model, most public health officials agree that the model has serious drawbacks that limit its effectiveness as a public health measure in all cases of infectious diseases.[40] These drawbacks are particularly evident in the failure of past attempts to apply the model to control the spread of sexually transmitted diseases (STDs).[41]

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[39] This outline is, of course, premised on the assumption that no vaccine is available which, once administered to the population in question, would in the best circumstance eliminate the possibility of any new incidence of the disease. In the event that a vaccine is available, identification, as an infection control device, is usually rendered unnecessary. In the past, the follow-up program of infection control has frequently focused on invasive measures such as compulsory treatment to reduce or eliminate infectivity. In the absence of any effective treatment, invasive measures might include the mandatory exclusion of infected persons from settings or activities that may result in transmission, as well as the possibility of isolation. However, the ability to identify infectious persons does not always result in exclusively coercive measures. Identification can be voluntary, can result in treatment with the consent of the infected person, and can produce voluntary behaviour modification that will reduce or eliminate any risk of infection to a third party.

[40] See, for example, Fee and Fox (eds.), *AIDS: The Burdens of History* (1988).

[41] *Ibid.* In the past the stigma associated with STDs seriously restricted the ability of the biomedical model either to identify infectious persons or to sever routes of transmission. Measures to identify infected persons were hampered by fears of stigmatization and prejudice. Those who knew that they might be at risk for infection learned ways to evade

A great weakness of the biomedical model, now widely recognized, is that it focuses almost exclusively on the identification and control of persons already infected. Attempts to educate those who are not infected, yet perhaps are at some risk of infection, are largely overlooked. Social stigma and conventional morality continue to limit widespread and straightforward education efforts aimed at informing the public of simple preventive measures. The biomedical model also is heavily dependent on available technology: in the absence of accurate, inexpensive, and easily accessible tests or treatments, the model quickly breaks down. If a test is unreliable, infected persons will escape detection or treatment, as was the case until recently with carriers of syphilis and gonorrhea.[42] If no easy and effective treatment is available, the remaining ways of interrupting transmission, such as exclusion or isolation, are costly.[43] For obvious reasons, such invasive measures meet with resistance on the part of the affected population, making universal or even widespread compliance impossible. As a result, those measures have a predictably weak record in limiting the spread of infection.[44]

(ii) Testing of the Entire Population

Because there is no readily available and effective treatment for HIV infection, the limits of the classical model of infection control are evident. For this reason, it is generally agreed that the implementation of widespread mandatory HIV antibody testing would constitute a vast waste of resources and do little to combat the spread of HIV.[45] Nonetheless, under the provisions of the HPPA, provincial public health officials can require an HIV antibody test of any person in Ontario if such a measure is necessary to prevent the spread of infection. This legislative authority could, technically speaking, permit the mandatory testing of all persons in Ontario. The local medical officer of health has the authority to identify, treat, or isolate persons with communicable diseases. Under the regulatory power available to the

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identification by public health authorities. Follow-up measures to control the spread of the infection may only have increased the fear of identification, particularly if those measures were highly invasive, coercive, or threatening (such as isolation) or if they resulted in the disclosure of highly sensitive identifying information (as in partner notification). See, generally, Brandt, *supra*, note 37.

[42] Cassel, *supra*, note 37.

[43] For example, in the United States during World War I, prostitutes were routinely subject to detention and isolation for a number of STDs. See Brandt, *supra*, note 37, at 233.

[44] See, generally, Brandt, *ibid.*

[45] See, for example, *Confronting AIDS: Update 1988*, *supra*, note 18, at 120, where the National Academy of Sciences states: "Mandatory screening of the entire U.S. population for HIV infection at the present time would be impossible to justify on either ethical or practical grounds."

Minister of Health under the HPPA,[46] AIDS has been defined as both a reportable and a communicable disease.[47] AIDS has not been defined as a "virulent" disease.[48] If the medical officer of health is "of the opinion, upon reasonable and probable grounds, (*a*) that a communicable disease exists or may exist or that there is an immediate risk of an outbreak of a communicable disease in the health unit served by the medical officer of health; (*b*) that the communicable disease presents a risk to the health of persons in the health unit served by the medical officer of health; and (*c*) that the requirements specified in the order are necessary in order to decrease or eliminate the risk to health presented by the communicable disease",[49] the officer may order any person to "submit to an examination by a physician and to deliver to the medical officer of health a report by the physician as to whether or not the person has a communicable disease or is or is not infected with an agent of a communicable disease".[50]

There are remedies available to the medical officer of health in the event that a person subject to an order fails to comply: the person will have committed an offence under the HPPA,[51] and will be liable on conviction to a fine of not more than $5,000 for every day the offence continues.[52] The contravention of any order issued under the HPPA may be enforced by a court order.[53]

For a number of reasons, universal mandatory testing for HIV infection cannot reasonably be regarded as effectively furthering any public health objective. First, the necessary technology for the successful implementation of such a program is lacking. For a number of technical reasons, the current HIV antibody test can fail to detect a person who is HIV-infected (that is, the test can produce a false negative) or can erroneously identify a person as HIV-infected (a false positive). If this test is used in a population where the overall seroprevalence rate is low, as is the case in Ontario and Canada, a mass mandatory testing program for HIV infection would fail to identify all infected persons, and would incorrectly identify others as HIV-infected.[54] Because the biomedical model relies heavily on the accuracy of identification, it tends to obscure the importance of public health educational efforts to inform the public of simple preventive measures to avoid infection. Of even greater importance is the lack of a readily available and effective treatment for HIV infection. At best, the treatments only slow the progression of the disease; there is no evidence that they halt or reverse that progression. Despite the absence of an effective treatment to eliminate infectivity or halt disease progression, there are ways in which identifying information can be used to prevent further transmission of disease.

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[46] HPPA, s. 97.

[47] O.Regs. 162/84, 161/84. Although the regulations only specify that "AIDS" is a reportable disease, this provision has been interpreted as requiring the reporting of all findings of HIV seropositivity, because an individual who is HIV-infected "is or may be infected with an agent of a communicable disease" (s. 26). See, also, Flanagan, "Equality Rights for People with AIDS: Mandatory Reporting of HIV Infection and Contact Tracing" (1989), 34 McGill L.J. 530, at 552-53.

[48] Although this has been proposed, AIDS has not been defined as "virulent". The medical officer of health enjoys even broader powers to control the spread of virulent diseases: see, for example, HPPA, s. 35.

[49] *Ibid.*, s. 22(2)(*a*)-(*c*).

[50] *Ibid.*, s. 22(4)(*f*).

[51] *Ibid.*, s. 100.

[52] *Ibid.*, s. 101.

[53] *Ibid.*, s. 102.

First, identification may assist in public health efforts to encourage behaviour modification. Many targeted public health education campaigns have achieved notable success in the reduction of high-risk behaviour, particularly among gay men.[55] It has been proposed that once individuals know they are HIV-infected, they may be more likely to alter their high-risk behaviour so as to reduce the risk of transmission. But the data on this point are scant, and there is no clear evidence that HIV testing plays a substantial role in motivating behavioural change.[56] To date, most studies report no consistent effect of knowledge of HIV status on subsequent behaviour. Similar results have been reported with injection drug users.[57] Scarce resources would be more effectively spent on general efforts at public education, with a specific, culturally responsive[58] focus on individuals engaging in high-risk activity. But even if it is of little utility in encouraging behaviour modification, identification could still be used to prevent further transmission if all those identified as infected could be isolated.[59]

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[54] This is because the proportional number of false positives will be greater than it would be in a population where the seroprevalence rate was higher: *supra*, ch. 1, sec. 4(d). The consequences of imperfect testing technology are evident. People incorrectly identified as HIV negative might fail to take precautions, and persons incorrectly identified as HIV positive would suffer the consequences of an inaccurate identification.

[55] Valdiserri, *supra*, note 37, at 147-49.

[56] *Ibid.*, at 233-34.

[57] *Ibid.*, at 235.

[58] Education efforts targeted at groups engaging in high-risk behaviour must be presented in terms members of these groups will find "relevant, realistic, and acceptable", reflecting a consideration of "the special characteristics, needs, and preferences of its target group members". This factor is critical is ensuring the success of any such program: *ibid.*, at 94-95.

The costs in human and economic terms of isolating all HIV-infected persons (including those incorrectly identified as HIV-infected) are unimaginable. Many thousands of Canadians may currently be infected with HIV,[60] and most of those people will remain in good health for years after initial infection. Because there is no risk of the casual transmission of HIV infection to the public as a whole, isolation has never been seriously considered as either a humane or an effective response to this epidemic.[61]

Universal testing cannot be regarded as furthering a public health objective. Such a program would be feasible only if there existed a highly accurate means of identifying infected persons, a readily available treatment that could effectively treat the disease and eliminate infectivity, and the necessary resources to implement both measures.

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[59] Although the terms "isolation" and "quarantine" are often used interchangeably, there is a technical distinction between them. "Isolation" is the separation of infected persons during the period of communicability in order to prevent further transmission of the infectious agent. "Quarantine" is the detention of persons who are healthy, but have been exposed to a communicable disease, so as to prevent contact with persons who have not been exposed. Because proposals for confining persons with AIDS tend to target persons who are HIV-infected or who exhibit other symptoms of the disease, "isolation" is the more appropriate term. See Gostin, "The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties" (1989), 49 Ohio St. L. J. 1017, at 1026-27.

[60] See *HIV and AIDS: Canada's Blueprint*, *supra*, note 17, at 14.

[61] With the notable exception of Cuba, isolation for HIV infection has never been implemented anywhere in the world. See Bayer and Healton, "Controlling AIDS in Cuba" (1989), 15 New Eng. J. Med. 1022; Gostin, *supra*, note 59, at 1027. A slightly less invasive alternative to isolation is available. The HIV status of infected persons could be disclosed to any or all uninfected persons, thereby permitting the uninfected persons to take precautions to avoid transmission. It has been suggested that HIV-infected persons be branded or tattooed: see, for example, Buckley, "Identify all the Carriers", *The New York Times* (March 18, 1986). Alternatively, all the contacts of the infected person, such as spouses, employers, sexual partners, and public health officials, could be directly informed of the person's status. This procedure would eliminate the confidentiality of HIV-related information. The economic costs of universal testing would still be enormous, and the program would fail to identify all infected persons, not only because of the limitations of current HIV antibody tests but because of the widespread attempts to evade identification that the program would precipitate. Moreover, although mandatory disclosure in the form of contact tracing may be appropriate in certain circumstances, it is not clear that the limited benefits of contact tracing would justify the imposition of a hugely expensive scheme of mandatory HIV testing. HIV infection is easily preventable by avoiding high-risk activity, and public funds could be spent much more wisely and economically on education programs rather than on the identification and mandatory disclosure of all individual cases of HIV infection.

(iii) Testing of "High-Risk Groups"

It is sometimes suggested that many of the problems associated with universal mandatory HIV testing could be avoided if mandatory testing were confined solely to the "high-risk groups"—that is, to groups with a comparatively high incidence of infection, such as gay men, bisexual men, injection drug users, haemophiliacs, and their sexual partners. Those identified as HIV-infected could be encouraged to avoid high-risk activity, or some form of mandatory disclosure or even isolation could be employed. Would the testing of high-risk groups reasonably fall within the scope of the HPPA?

The HPPA would permit the selective application of mandatory HIV tests to high-risk groups only if a medical officer of health could successfully argue that there was "an immediate risk of an outbreak of" HIV infection that presented "a risk to the health of persons in the health unit" and was "necessary in order to decrease or eliminate the risk to health presented" by HIV infection.[62]

But even if this argument were advanced, it is the consensus of public health officials that selective testing of high-risk groups would be unlikely to limit the spread of infection[63]—first, because no effective treatment is available and, second, because selective testing of high-risk groups would fail to identify all infected persons. The likelihood of infection is a function of high-risk activity, not of membership in a group. Persons can easily be a member of one of the high-risk groups yet take all necessary precautions to avoid transmission. Persons can also engage in high-risk activity and yet not recognize themselves as members of one of the groups. Women might engage in unprotected sexual relations with men who fail to disclose that they are bisexual or injection drug users. These women are at risk of infection, yet obviously would not regard themselves as members of one of the groups. Selective HIV testing of groups would probably fail to identify many persons at risk. Even those individuals who do identify themselves as members of a particular group cannot be expected to present themselves to public health officials for the purposes of a mandatory testing program.[64] As with any large-scale testing and counselling program, the costs of the selective mandatory testing of high-risk groups would be high. Human costs, including the possibility of isolation or mandatory disclosure, would be imposed not only on persons identified as HIV-infected, but on groups of persons, and the benefits of the program would be few. It would fail to identify a large number of HIV-infected persons, and would deflect public attention and resources away from general efforts to educate the public about risk reduction.

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[62] HPPA, s. 22 (2).

[63] See, for example, *Confronting AIDS: Update 1988*, *supra*, note 18, at 120, where the National Academy of Sciences states that "the committee is opposed to the mandatory screening of population subgroups" such as gay men or injection drug users.

[64] Gay men share a history of discrimination and criminalization of their sexual activity and are unlikely to disclose their status as members of a high-risk group.

In other words, despite the language of the HPPA, a medical officer of health would be unable to argue convincingly that selective testing of high-risk groups was "necessary in order to decrease or eliminate the risk" presented by HIV infection.[65] The Commission believes that alternative measures, such as a targeted public health education campaign directed at persons engaging in high-risk behaviour coupled with wide availability of voluntary HIV antibody testing, would be both less costly and more effective to reduce transmission within these groups. No exception to the rule requiring voluntary, specific, and informed consent is justified with respect to high-risk groups.

(b) DISCRIMINATION AND THE HUMAN RIGHTS JURISPRUDENCE

Legal measures have been developed to protect HIV-infected persons from unwarranted discrimination.[66] The protection that has been extended to HIV-infected persons has arisen largely under the anti-discrimination legislation available to the physically disabled. In 1987 the Supreme Court of the United States delivered its crucial decision in *School Board of Nassau County, Florida v. Arline*,[67] wherein the Court held that the sufferer of an infectious and communicable disease, in this case tuberculosis, was entitled to the protection available to the physically disabled under the *Rehabilitation Act of 1973*.[68] Since *Arline* an extensive line of judicial precedents in the

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[65] HPPA, s. 22(2)(*c*).

[66] A fairly comprehensive survey of AIDS-related discrimination in the United States was recently completed by the American Civil Liberties Association. See American Civil Liberties Association AIDS Project, *Epidemic of Fear: A Survey of AIDS Discrimination in the 1980s and Policy Recommendations for the 1990s* (1990).

[67] 480 U.S. 273, 94 L.Ed. 2d 307, 107 S. Ct. 1123 (1987); rehearing den. 481 U.S. 1024, 107 S.Ct. 1913*n* (1987) (subsequent references are to 107 S.Ct.) (hereinafter referred to as "*Arline*"). See Flanagan, *supra*, note 47, at 568-80.

[68] 29 U.S.C. §§701-96 (1982). The Rehabilitation Act of 1973 (hereinafter referred to as "Rehabilitation Act"), which governs federal employees, federal contractors, and programs receiving federal financial assistance, generally prohibits discrimination on the basis of a physical disability. Because the Act has a limited jurisdiction, it does not provide comprehensive national protection against discrimination on the basis of a physical disability.

United States has extended anti-discrimination protection to all HIV-infected persons.[69]

The importance of this legal development cannot be overestimated. Before *Arline* the federal Justice Department had argued that discrimination based on the fear of infectious transmission was not prohibited by the *Rehabilitation Act* and that discrimination against persons who were HIV-infected yet suffered no manifest physical impairment raised no issue of discrimination against the physically disabled.[70] In *Arline*, the court rejected this reasoning. It held not only that the sufferer of an *infectious* disease was entitled to legal protection, but that the *asymptomatic* sufferer of an infectious disease was also entitled to protection. Notwithstanding that some carriers of infectious disease may present a risk of infection to others, or that others may suffer no manifest physical symptoms of any disability, the court held that they are nonetheless entitled to the protection available under the *Rehabilitation Act*. It concluded:[71]

> [S]ociety's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment. Few aspects of a handicap give rise to the same level of public fear and misapprehension as contagiousness.... The fact that *some* persons who have contagious diseases may pose a serious health threat to others under certain

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[69] Although the Court in *Arline, supra*, note 67, at 1128 *n*. 7, expressly declined to address the issue of whether HIV infection could constitute a physical handicap under the legislation, subsequent decisions of lower courts have extended the application of the Act both to individuals who have developed AIDS and to those who have asymptomatic HIV infection. See, for example, *Chalk v. United States Court, Central District of California*, 840 F.2d 701 (9th Cir., 1988); and *Doe v. Centinela Hospital*, 57 U.S.L.W. 2034 (D.C. Cal., 1988).

[70] In 1986 the Office of Legal Counsel of the United States Justice Department issued an advisory opinion finding that discrimination based on fears of contagion was not prohibited by the Rehabilitation Act. However, the courts, and now even the Justice Department, agree that §504 of the Act may apply to discrimination against individuals with HIV infection, whether they are symptomatic or whether the discrimination is due to fears of contagion. See Parmet, "An Antidiscrimination Law: Necessary but Not Sufficient", in Gostin (ed.), *AIDS and the Health Care System* (1990) 85, at 87. Relying upon §504 of the Rehabilitation Act, courts have granted relief to students denied the opportunity to attend school because of their HIV status and to employees discharged from their jobs because of their infection. See, for example, *Martinez v. School Bd.*, 861 F.2d 1502 (11th Cir. 1988); *Chalk v. United States Dist. Court, Central Dist. of Cal.*, *supra*, note 69; *Doe v. Dolton Elementary School District No. 148*, 694 F. Supp. 440 (N.D. Ill., 1988); *Robertson v. Granite City Community Unit School District No. 9*, 684 F. Supp. 1002 (S.D. Ill., 1988); *Ray v. School District*, 666 F. Supp. 1524 (M.D. Fla., 1987); *Thomas v. Atascadero Unified School District*, 662 F. Supp. 376 (C.D. Cal., 1987); *District 27 Community School Board v. Board of Education*, 502 N.Y.S. 2d 325, 130 Misc. 2d 398 (N.Y.S.Ct., 1986).

[71] *Arline*, *supra*, note 67, at 1129-30.

circumstances does not justify excluding from the coverage of the Act *all* persons with actual or perceived contagious diseases.

This judicial advance was followed three years later with the passage of the historic *Americans With Disabilities Act* (ADA).[72] Whereas the *Rehabilitation Act* applies only to the federal government and programs receiving federal assistance, the ADA provides comprehensive protection against discrimination on the basis of physical disability, including HIV infection, not only in federally funded entities but also in state-funded entities, private employment, and public accommodations that are privately owned. In the United States, the combination of *Arline* and the ADA have greatly added to protection from discrimination for HIV-infected persons.[73]

In Ontario, the *Human Rights Code*[74] governs private and public actions that fall within provincial jurisdiction. The *Canadian Human Rights Act*[75] governs private and public actions that fall within federal jurisdiction. The human rights legislation provides comprehensive protection for HIV-infected persons in the province.[76] The Ontario Code prohibits discrimination on the basis of a "handicap",[77] and thereby ensures that the disabled are entitled to protection in respect of employment, housing, contracts, and the provision of goods, services, and facilities, as set out in Part I of the Code. A handicapped person is defined as one who "has or has had, or is believed to have or have had, (i) any degree of physical disability...that is caused by...illness and, without limiting the generality of the foregoing, including diabetes mellitus, epilepsy, any degree of paralysis, amputation, [or] lack of physical coordination".[78] Since 1985 the Ontario

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[72] Pub.L. No.101-336, 104 Stat. 327 (1990) (hereinafter referred to as "ADA").

[73] See Burris, "Rationality Review and the Politics of Public Health" (1989), 34 Villanova L. Rev. 933, at 982, where the author concludes: "Taking *Arline* seriously, we may challenge courts to demand some reasonable medical basis for a health action, and to reject actions that proceed primarily from reflexive mythology."

[74] R.S.O. 1990, c. H.19 (hereinafter referred to as the "Code").

[75] R.S.C. 1985, c. H-6.

[76] For an overview of federal and provincial AIDS-related legislation, see McGill Centre For Medicine, Ethics and Law (AIDS Research Program), *Responding to HIV/AIDS in Canada*, by Hamblin *et al.* (1990) (hereinafter referred to as "*Responding to HIV/AIDS in Canada*").

[77] Code, ss. 1, 2, 3, 5, and 10.

[78] Code, s. 10(1)(*a*), which provides:

> "[B]ecause of handicap" means for the reason that the person has or has had, or is believed to have or have had,
>
> (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting

Human Rights Commission (OHRC) has recognized that AIDS, as an illness, falls within the definition of "handicap" found in the Code.[79] Consistent with the American judicial and legislative precedents considered above, the OHRC has also interpreted this protection as extending to *all* persons infected with HIV, including those who are asymptomatic.[80]

In addition to the general prohibition of discrimination on the basis of physical disability, the Ontario Code prohibits "harassment" on the basis of a handicap—that is, "a course of vexatious comment or conduct that is known or ought reasonably to be known to be unwelcome".[81] The Code also prohibits discrimination based on "a relationship, association or dealing"[82] with a physically disabled person. Finally, discrimination on the ground of "sexual orientation"[83] is prohibited.[84]

Although a decision on the question has not yet been rendered in Ontario, there are at least two reported Canadian decisions in which it was held that HIV infection constitutes a physical disability. In the first of these decisions, *Biggs v. Hudson*,[85] the British Columbia Human Rights Council held that "[a]ny person who is seropositive by manifesting antibodies to HIV has a physical disability and, in the absence of a *bona fide* occupational requirement, if applicable, is entitled to the protection" of the British Columbia *Human Rights Act*.[86] A decision of the Canadian Human Rights Tribunal held in *Fontaine v. Canadian Pacific Ltd.*[87] that an HIV-infected camp cook was a physically disabled person under section 3(1) of the

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the generality of the foregoing, including diabetes mellitus, epilepsy, any degree of paralysis, amputation, lack of physical coordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or on a wheelchair or other remedial appliance or device.

[79] Ontario Human Rights Commission, *Policy Statement on HIV/AIDS-Related Discrimination* (hereinafter referred to as "O.H.R.C. *Policy Statement*").

[80] *Ibid.*

[81] Code, s. 10.

[82] Code, s. 12.

[83] Code, ss. 1, 2, 3, and 5.

[84] This provides additional protection to one of the groups identified as being at higher risk of HIV infection.

[85] (1988), 9 C.H.R.R. D/5391, at D/5394.

[86] S.B.C. 1984, c. 22.

[87] (1990), 11 C.H.R.R. D/288, at D/294; aff'd *infra*, note 88.

Canadian Human Rights Act.[88] Finally, an Alberta Board of Inquiry in *S.T.E. v. Bertelsen*[89] held that AIDS constitutes a physical disability under the *Individual's Rights Protection Act.*[90]

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[88] The defendant conceded that HIV infection is a disability under the *Canadian Human Rights Act*, S.C. 1976-77, c. 33, and no argument was presented to the Tribunal on this issue: *Fontaine v. Canadian Pacific Ltd.*, *supra*, note 87, at D/294. On appeal on other grounds to the Federal Court of Appeal, the Tribunal's decision was upheld: See *Canadian Pacific Ltd. v. Canadian Human Rights Commission* (1990), 91 C.L.L.C. ¶16,197 (F.C.C.A.).

[89] (1989), 10 C.H.R.R. D/6294, at D/6296, 89 CLLC ¶17,017, at 16,134 (subsequent references are to 10 C.H.R.R.). Again, the defendant conceded that AIDS was a physical disability under the Act and no argument was heard on this issue. Unlike *Biggs v. Hudson, supra*, note 85, and *Fontaine v. Canadian Pacific Ltd., supra*, note 87, because *S.T.E. v. Bertelsen*, *supra*, only refers to "AIDS" as a covered physical disability, the decision arguably does not address the question of whether all aspects of HIV infection, including asymptomatic HIV infection, constitute a physical disability.

[90] R.S.A. 1980, c. I-2. Although the issue has not been considered specifically by any court, it is likely that the courts, consistent with the human rights decisions described above, would find HIV infection to be a physical disability under s. 15, the equality section of the *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B of the *Canada Act 1982* (U.K.), 1982, c. 11 (hereinafter referred to as the "Charter"), which provides: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

There are only a few reported decisions concerning the scope of physical disability under s. 15 of the Charter. For example, in *Fenton v. Forensic Psychiatric Services Commission* (1989), 29 C.C.E.L. 169 (B.C.S.C.), the Court held that s. 8(2)(d) of the *Employment Standards Act Regulations*, B.C. Reg. 37/81, which exempted employers from paying minimum wage where their disabled employees were employed with a charity and receiving occupational rehabilitation, resulted in discriminatory treatment that could not be justified under s. 1 of the Charter. Of course, the Charter is limited to the review of state action as it has been defined by the Supreme Court of Canada in *R.W.D.S.U. v. Dolphin Delivery Ltd.*, [1986] 2 S.C.R. 573, 33 D.L.R. (4th) 174, and *Re McKinney and Board of Governors of the University of Guelph* (1990), 91 CLLC ¶17,004 (S.C.C.). Nonetheless, the *potential* application of the Charter in the context of HIV infection could be far-reaching. Legislative provisions and government action that could be challenged under the Charter might include HIV-related testing requirements, compulsory nominal reporting of HIV infection and AIDS, and quarantine and isolation provisions. See *Responding to HIV/AIDS in Canada*, *supra*, note 76, at 2-34.

In addition to s. 15, other Charter provisions that might be relied upon in a potential challenge include: s. 7, which states that "[e]veryone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice"; s. 8, which enacts the principle of security against unreasonable search and seizure; s. 9, which concerns the right not to be arbitrarily detained or imprisoned; and s. 12, which concerns the right not to be subjected to any cruel and unusual treatment or punishment. Whether *any* future Charter challenge is successful will depend to a large extent on the approach adopted by the Canadian courts in deciding what limits on individual rights can be "demonstrably justified in a free and democratic society". See *Responding to HIV/AIDS in Canada*, *supra*, note 76, at 2-33.

The Ontario *Human Rights Code* also states that the right to equal treatment with respect to employment is infringed where a prospective employer makes any direct or indirect inquiry that "classifies or indicates qualifications by a prohibited ground of discrimination".[91] The OHRC has issued a policy stating that employers cannot therefore subject job applicants to any type of medical examination, including an HIV test,[92] before an offer of employment. After the applicant is hired, only medical tests that relate to a *bona fide* occupational qualification (BFOQ) are permitted,[93] and then only if the physically disabled person cannot be accommodated without undue hardship to the employer.[94]

There is considerable jurisprudence on what may constitute a *bona fide* occupational qualification in any given job.[95] The Ontario Human Rights Commission has said that "in the vast majority of work settings, it is unlikely that testing or other protective measures would be permitted as persons with HIV infection or HIV-related illness pose virtually no risk to those with whom they interact".[96] In the language of the Code, because HIV infection itself would not render a person "incapable of performing or fulfilling the essential duties or requirements"[97] of employment, HIV testing of employees and job applicants would not be permitted under the human rights legislation in Ontario.

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[91] Code, s. 23(2).

[92] *Ontario Human Rights Commission Policy on Employment-Related Medical Information* (April, 1990) (hereinafter referred to as *O.H.R.C. Policy on Employment-Related Medical Information*).

[93] Section 17(1) of the Code provides: "A right of a person under this Act is not infringed for the reason only that the person is incapable of performing or fulfilling the essential duties or requirements attending the exercise of the right because of handicap." If the disability is a reasonable and *bona fide* concern with regard to the job performed, discrimination on these grounds may be permitted.

[94] Section 17(2) of the Code provides: "The Commission, a board of inquiry or a court shall not find a person incapable unless it is satisfied that the needs of the person cannot be accommodated without undue hardship on the person responsible for accommodating those needs, considering the cost, outside sources of funding, if any, and health and safety requirements, if any."

[95] See, for example, *Central Alberta Dairy Pool v. Alberta Human Rights Commission*, [1990] 2 S.C.R. 489, 33 C.C.E.L. 1. The question what may constitute a *bona fide* occupational qualification was also considered by the U.S. Supreme Court in *Arline*, *supra*, note 67, which held that in the context of an infectious disease it is particularly important to recognize the legitimate need to prevent exposing others to significant health and safety risks. The court held that a person who poses a significant risk of communicating an infectious disease to others in the workplace would not be "otherwise qualified" for his or her job. However, the court also held that persons with infectious diseases are entitled to "an individualized inquiry" to determine whether their condition presents a significant health and safety risk to others; the courts must base their finding on reasonable medical judgments about the nature, duration, and severity of the risk of infection. In *Arline* the court stressed the importance of relying on scientific and medical evidence of the risk of infection rather than on "prejudice, stereotypes, or unfounded fears": *Arline, ibid.*, at 1131, *n.* 16. See, also, ADA, *supra*, note 72, §103.

[96] *O.H.R.C. Policy Statement on HIV/AIDS-Related Discrimination*, *supra*, note 92. The current policy adopted by the Canadian Human Rights Commission (May, 1988) provides that HIV infection will be considered a disability under the provisions of the *Canadian*

3. TESTING SPECIFIC POPULATIONS

The human rights jurisprudence serves to underscore the necessity of providing a carefully articulated rationale, closely related to a legitimate public health objective,[98] for any mandatory or compulsory HIV testing scheme. In the following section of this report we will consider whether the involuntary HIV-related testing of any of the specific populations described below can meet this requirement.[99]

(a) DONORS OF BLOOD PRODUCTS OR BODILY TISSUES

The mandatory HIV antibody testing of donors of blood, organs, tissue, ova, semen, or other human body parts and fluids has been universally

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Human Rights Act, *supra*, note 75. The policy also states that HIV infection may constitute a BFOQ where an essential requirement of the position is that the employee "perform invasive procedures" (this presumably includes surgeons or dentists) or "perform job duties which impinge on the safety of the public and performs these duties alone" (this presumably includes someone like an air-traffic controller). In this respect, the Canadian Human Rights Commission contemplates much broader grounds on which an HIV-infected person can be excluded from a given workplace. But in the vast majority of workplace settings, HIV-infected persons present no risk of infection to their co-workers.

In *S.T.E. v. Bertelsen*, *supra*, note 89, at D/6301, for example, the complainant played in a band at a hotel and lived with his fellow players in an apartment supplied by the hotel. He was dismissed because he was HIV-infected and the employer feared the possibility of HIV transmission, particularly in their living accommodations. The board of inquiry held that "there [was] no credible scientific data" to support the employer's concerns, as the "experts were unanimously of the opinion that there is no risk of infection in a normal household environment and no need for the infected person to inform household members of his condition."

In *Fontaine v. Canadian Pacific Ltd.*, *supra*, note 87, at D/294, the respondent C.P. Ltd. conceded that HIV infection was not a valid BFOQ of any job function within their company, including the handling of food. An arbitration board came to a similar conclusion with respect to flight attendants in *Re Pacific Western Airlines Ltd. and Canadian Air Line Flight Attendants Association* (1987), 28 L.A.C. (3d) 291, [1987] T.A. 589.

[97] Code, s. 17.

[98] In some cases, such as in life and health insurance, the rationale may instead be an economic one. *Supra*, this ch., sec. 3(g).

[99] It follows from the discussion above that the testing of the entire population or testing of high-risk "groups" would fail to meet this minimum requirement.

endorsed by public health officials as an essential and effective means of preventing the spread of HIV infection.[100] Early in the epidemic it was realized that HIV can be transmitted by contaminated blood via transfusion. Even before HIV was identified, procedures were introduced to reduce the risk associated with blood transfusions, such as the exclusion of donors who were at a high risk for the disease.[101] With the development of the HIV antibody test in 1985, mandatory HIV testing was imposed on all blood donors in Canada.[102] Although the current test will not detect all HIV-infected donors, the introduction of HIV testing has nonetheless greatly improved the safety of the blood supply.[103] The testing of donated blood, body parts, or body fluids for use in medical research, therapy, or transplantation has been broadly endorsed and implemented because it is a highly effective means of preventing HIV infection.

Blood and blood products are regulated primarily by the *Food and Drugs Act*[104] under the jurisdiction of the federal Minister of National Health and Welfare. The Act defines a drug as, *inter alia*, any substance used for the purposes of treatment or prevention of disease; that definition is broad enough to include blood.[105] The Bureau of Biologics of the Department of National Health and Welfare is the federal body responsible for the licensing of drugs prepared from tissues of human origin, such as blood. The decision to begin testing all blood and flood products for HIV antibody as of November 1, 1985, was agreed upon by the Canadian Red

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[100] Somerville and Gilmore, *supra*, note 18, at 26. It has, however, been suggested that the screening of blood donors is not optimally cost-effective. Rather than spending a comparatively large amount of money on screening all blood donors in order to prevent a fairly small number of new infections (at an estimated cost of $124,000 for each donor identified as HIV-infected), these funds might be better spent on explicit AIDS education efforts directed at gays, teens, and needle-sharing injection drug users: see Gunderson, Mayo, and Rhame, *AIDS: Testing and Privacy* (1989), at 194-95. The authors conclude that the cost can be justified by other benefits, such as the comfort and reassurance screening provides to people who receive blood products.

[101] Miller, Turner, and Moses (eds.), *AIDS: The Second Decade* (1990), at 291.

[102] Rodgers, "The Canadian Blood Delivery System: Liability for Blood Related Injuries" (1989), 21 Ottawa L. Rev. 311, at 327. Testing has also long been conducted for a number of other conditions, including hepatitis and syphilis.

[103] For example, in the United States, it is estimated that before the introduction of HIV testing of blood donors, as many as 4,000 blood recipients a year received blood infected with HIV. With the implementation of testing, this number has probably been reduced to about 100 (a projection based on the estimate that there is a 1 in 34,000 risk that a blood recipient of an average number of blood units may receive HIV-infected blood). See *Confronting AIDS: Update 1988*, *supra*, note 18, at 309-13. The risk figure is probably even lower in Canada, where the seroprevalence rate is less than one-half that of the United States.

[104] R.S.C. 1985, c. F-27.

[105] Rodgers, *supra*, note 102, at 324.

Cross Society, the National Advisory Committee on AIDS, and the AIDS-Associated Retrovirus Testing Task Force.[106]

Although mandatory HIV testing of blood donors has improved the safety of the blood supply, because of the technological limitations of our current HIV antibody test, not all infected donors will be detected by the current HIV antibody test. A small fraction of false negatives will result, largely because of the length of time between infection and the production of antibodies.[107] During this "window" period, the blood collected from an infected donor may test negative. For this reason, it is essential that persons at a high risk of HIV infection must be encouraged to self-exclude.[108] To facilitate self-exclusion, blood collection agencies help donors appreciate what behaviour may have placed them at risk in the past, such as unsafe homosexual activity and injection drug use.[109] Self-exclusion is best done in a completely confidential manner.[110] Questions about high-risk behaviour should be asked in private, and donors should be able to state in private that their blood should not be used for the purposes of transfusion. This process is known as "confidential unit exclusion", or CUE, and enables potential donors to self-exclude without drawing the attention of co-workers or other donors.

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[106] Canadian Red Cross Society, Nusbacher, submission to Ontario Law Reform Commission on testing for HIV-infection (April 19, 1991), at 2.

[107] Generally, this period is no longer than a few months, although one study indicated that in some cases it may take many months before an infected person produces HIV antibodies. See Miller, Turner, and Moses, *supra*, note 101, at 291.

[108] In the case of *R. v. Thornton*, Ont. Dist. Ct. (Ottawa-Carleton Doc. No. 759/89), August 14, 1989; aff'd (1991), 1 O.R. (3d) 480 (C.A.), the accused was convicted of a common nuisance under s. 180 of the *Criminal Code*, R.S.C. 1985, c. C-46, because he donated blood to the Canadian Red Cross while knowing that he was HIV-infected. The accused had argued that he donated the blood thinking that this might "expel the disease from his body". The accused also argued that he was under the mistaken impression that the HIV screening process employed by the Red Cross was 100 percent effective in identifying infected blood and he was therefore confident that his blood would be discarded.

Not only was the accused aware that he was at a high risk of infection, he had in fact tested positive for HIV infection on two previous occasions. He nonetheless chose to donate blood and in the opinion of the trial judge thereby showed a "rash want of care for the lives of others".

[109] Miller, Turner, and Moses, *supra*, note 101, at 329.

[110] Measures to encourage donor self-exclusion have been extensively studied. Most important, donors must be helped to appreciate behaviour that may have placed them at risk in the past, and must be assured that they can select self-exclusion in a completely confidential manner. See, generally, *ibid.*, at 289-358.

The Canadian Red Cross currently employs a Donor Health Assessment Questionnaire[111] designed to facilitate exclusion. The questionnaire first asks blood donors a number of questions designed to identify persons who may be at a high risk of HIV infection. Donors are required to complete and sign the questionnaire, which includes a statement confirming that they understand that their blood will be tested for a number of diseases, including AIDS. In addition, donors must complete a Blood Safety Form, which permits them to exclude their blood for transfusion purposes in a confidential manner. High-risk activities are described in explicit language; if the donor has participated in any of those activities, he or she is asked to check the box indicating that blood is not to be used for transfusion purposes. The form is then sealed by the donor before it is returned to the Red Cross official. These procedures are consistent with the objective of identifying donors at risk of HIV infection and encouraging donor self-exclusion, thereby assuring the reasonable safety of the blood supply. Donors are expressly informed that their blood will be tested for the presence of the HIV antibody and that a positive result will be reported to the Public Health Department where required by provincial law.[112] They are also given a two-page information sheet describing AIDS, the ways in which it is transmitted, the meaning of an HIV test, and the procedure whereby a donor will be informed of a positive test result.[113] These procedures are consistent with the need to provide adequate information about the nature and purpose of an HIV-related test whenever a test is performed.[114]

The current regulation and practice in the area of human tissue donation, including semen, is less clear. The *Human Tissue Gift Act*[115] deals with the donation of human tissue for transplantation purposes. "Tissue" includes an organ, but "does not include any skin, bone, blood constituent or other tissue that is replaceable by natural processes of repair".[116] This means that semen donated for reproduction purposes is not covered by the Act. Because ova are not replaced by natural processes, they are covered.[117] In the case of *inter vivos* gifts for transplants, the Act provides that once a person consents to the removal of the tissue, the physician assumes the "full authority" to "make any examination necessary to assure medical acceptability of the tissue".[118] In all cases of human tissue donation, the Commission believes that prospective donors should be informed *before* the performance of the test that an HIV-related test will be conducted, and given adequate information about the nature and purpose of the test. The Commission recommends that, subject to the recommendation in section 5 (Epidemiological Screening) of this chapter, the HIV-specific statute should provide that no HIV-related test should be performed without first receiving voluntary, specific, and informed consent of the patient, except where an HIV-related test is performed in relation to the use of blood, organs, tissue, or body parts in medical research, treatment, or transplantation.

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[111] Included in a submission to the Ontario Law Reform Commission, *supra*, note 106.

[112] *Ibid.* In Ontario, in all cases where the testing of blood, blood products, human tissue, semen, and ova is performed, if the donor is found to be infected, this test result must be reported to the provincial medical officer of health under the current mandatory reporting requirements found in the Ontario HPPA. AIDS has been defined as both a reportable and a communicable disease under the Act. Section 29(1) of the Act requires that operators of laboratories report "each case of a positive laboratory finding in respect of a reportable disease". Failure to make a required report is an offence under the Act and is punishable by a fine upon conviction.

See *infra*, ch. 3 for an examination of the reporting requirements under the Act and the proposed amendments to the current practice.

[113] Donors who test positive will receive a letter asking for their doctor's name. The donor's doctor will then explain the test results and arrange for follow-up.

[114] See *supra*, this ch., sec. 1(b), where the requirements for informed consent are considered.

[115] R.S.O. 1990, c. H.20.

(b) SCHOOL AND PRE-SCHOOL SETTING

In the early days of the epidemic, when the transmissibility of HIV infection was still poorly understood, there was a great deal of public concern about the possibility of the transmission of infection from child to child or from teacher to student in the school and pre-school setting. Instances of discrimination against HIV-infected schoolchildren received considerable attention.[119] However, numerous studies have established that there is no effective risk of HIV transmission in schools.[120] Therefore, the mandatory HIV testing of schoolchildren or any prejudicial treatment of HIV-infected children is unjustified.[121] Many schools have adopted policies that reaffirm the right of children with HIV infection to attend school and to be treated in the same way as any other child.[122] Consistent with the advances in scientific information and current legal requirements, the Ontario Public School Teachers' Federation has adopted a policy that rejects the mandatory HIV testing of schoolchildren and teachers and confirms the right of HIV-infected children to attend regular classes.[123] The Commission believes that no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified with respect to teachers or students.

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[116] *Ibid.*, s. 1 "tissue".

[117] See, for example, Ontario Law Reform Commission, *Report on Human Artificial Reproduction and Related Matters*, Vol. 1 (1985), at 60, which concludes that sperm is probably not covered by the *Human Tissue Gift Act*, *supra*, note 115. A woman's complement of ova is fixed and not replaceable; accordingly, ova would fall within the ambit of the Act.

[118] *Human Tissue Gift Act*, *supra*, note 115, s. 3(3)(*a*). In the case of *post mortem* gifts for transplants, consent can given by the donor or by certain specified relatives and other persons after the donor's death. The physician then has "full authority for the use of the body or the removal and use of the specified part or parts for the purpose specified". The legislation does not specify that the physician may conduct any necessary examination to assure medical acceptability (in contrast to *inter vivos* donation): see *ibid.*, ss. 4(1), 4(3), and 5(1).

[119] See White and Cunningham, *Ryan White: My Own Story* (1991), about the young boy from Indiana who was driven out of his school by a hostile and frightened local community.

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[120] See, for example, Rogers *et al.*, "Lack of Transmission of Human Immunodeficiency Virus From Infected Children to Their Household Contacts" (1990), 85 Pediatrics 210, where the authors conducted a large study of household contacts of preschool-aged children, that is, children who normally drool, mouth objects, bite, and are incontinent. HIV has been isolated in a number of body fluids so these behaviours might be expected to facilitate transmission. In fact, no cases of transmission were documented and the authors concluded that the risk of HIV transmission by household, school, day-care, or other nonsexual contact is extremely low.

[121] Likewise, there is no reason to believe that HIV-infected teachers present any risk of infection to their students. Nonetheless, an HIV-infected public school teacher in Nova Scotia was effectively driven out of the classroom by an alarmed community. Although the community's concern about any risk to their children was eventually resolved by public education, the community remained adamantly opposed to allowing the teacher to return to the school once he publicly acknowledged that he was gay.

The case provides a telling illustration of the continuing close connection between fear of HIV infection and prejudice on the basis of sexual orientation. In short, discrimination on the basis of sexual orientation can often serve as a means to legitimate discrimination against persons with HIV infection, discrimination that would otherwise be prohibited on the grounds of physical disability. For this reason, any comprehensive effort to reduce HIV-related discrimination requires, as a minimum, laws that prohibit not only discrimination on the basis of physical disability, but also discrimination on the basis of sexual orientation, as is the case in Ontario. See Cox, "HIV Carrier Gives Up Fight for Teaching Job", *The Globe and Mail*, Toronto (May 9, 1991) A10.

[122] Although instances of discrimination may have decreased, public attitudes remain difficult to change. A recent survey indicated that one out of five doctors and medical students would pull their children out of a class if a classmate were infected with HIV: "1 in 5 MDs Fears AIDS in Classroom", *The Toronto Star* (April 17, 1991) A28.

[123] See Ontario Public School Teachers' Federation, *1991-92 Handbook*, at 37.38. For a comprehensive treatment of the issue of HIV in the school, see Fraser, National Association of State Boards of Education, *Someone at School Has AIDS: A Guide to Developing Policies for Students and School Staff Members Who Are Infected with HIV* (1989).

(c) PATIENTS

Both mandatory and "routine" HIV testing occasionally have been proposed or practised in hospitals. Mandatory testing requires the testing of a patient without obtaining voluntary, specific, and informed consent before health care services are offered. "Routine" testing, which is much more common, might be performed on a patient's blood sample without informing the patient or obtaining the patient's specific, voluntary, and informed consent to perform an HIV-related test. Some reports have stated that this kind of routine testing has occurred in several hospitals in Ontario.[124]

Routine testing in health care settings is often proposed for three reasons.[125] First, routine testing is said to be appropriate for clinical purposes because the patient will receive optimal medical care. Second, it is said that if a health care worker is exposed to the blood of an HIV-infected patient whose status is known, the worker will be able to consider possible treatments, some of which may require immediate attention. The worker may also want to avoid high-risk behaviour until it can be conclusively established whether or not she has been infected. Finally, mandatory or routine testing is most commonly proposed for reasons of public health and infection control—that is, to assist in efforts to prevent the transmission of HIV in hospitals and, in particular, to protect health care workers from the risk of infection. Although it is evident that health care workers are at very little risk of becoming infected as a result of occupational exposures to the blood of HIV-infected patients,[126] the degree of the risk, and the most appropriate way to reduce the risk, have been much debated.

The hepatitis-B virus (HBV), not HIV, is the major occupational health hazard in the health care industry. In the United States, for example, the

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[124] See *supra*, this ch., sec. 1(b).

[125] See Bell, "HIV Infection in Health Care Workers: Occupational Risk and Prevention", in Gostin (ed.), *AIDS and the Health Care System* (1990) 115; and Brandt, Cleary, and Gostin, "Routine Hospital Testing for HIV: Health Policy Considerations", Gostin (ed.), *AIDS and the Health Care System* (1990) 125.

See, also, Furrow, "AIDS and the Health Care Provider: The Argument for Voluntary HIV Testing" (1989), 34 Villanova L. Rev. 823.

[126] See, for example, Gostin, "HIV-Infected Physicians and the Practice of Seriously Invasive Procedures" (1989), 19 Hastings Centre R. 32, at 33, which states: "Physicians performing seriously invasive procedures, such as surgeons, have a potential to cut or puncture their skin with sharp surgical instruments, needles, or bone fragments. Studies indicate that a surgeon will cut a glove in approximately one out of every four cases, and probably sustain a significant skin cut in one out of every forty cases. Given these data, it has been calculated that the risk of contracting HIV in a single surgical operation on an HIV-infected patient is remote—in the range of 1/130,000 to 1/4,500."

Centers for Disease Control (CDC) estimate that 500 to 600 health care workers whose jobs entail exposure to blood are hospitalized annually with HBV infection, and more than 200 of those die from the infection.[127]

By comparison, in the past ten years the CDC has documented approximately twenty cases of occupationally acquired HIV infections among the 6.9 million health care workers in the United States.[128] The workers were infected in one of two ways. First, and most commonly, they sustained percutaneous injuries (a needle-stick or a cut) with instruments contaminated with the blood of HIV-infected patients.[129] A smaller number appear to have been exposed to the blood of an HIV-infected patient through the mucous membrane (such as a splash to the eye or mouth) or after contact with non-intact skin (such as skin that was chapped, abraded, or afflicted with dermatitis). A prospective study undertaken by the CDC has established that the risk of HIV infection after a single needle-stick or injury with a sharp object contaminated with HIV-infected blood is about 0.4 percent.[130] The risk of HIV infection after a single episode of mucous membrane or non-intact skin exposure is considerably less and cannot be determined from existing data.[131]

The risk of infection, although small, is real. Proposals to reduce the risk have focused on two alternatives. The most broadly accepted and practised of the two is the introduction of "universal precautions" in health care settings, whereby the blood and certain bodily fluids of all patients are considered potentially infectious and treated accordingly.[132] These precautions include appropriate barrier precautions such as gloves, masks, goggles, and gowns, to prevent skin or mucous membrane exposure, especially in the case of invasive procedures, such as surgery. Injury prevention also includes the safe handling and disposal of used needles.[133]

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[127] See Gostin, "Preface: Hospitals, Health Care Professionals, and Persons with AIDS", in Gostin (ed.), *AIDS and the Health Care System* (1990), at 5-6.

[128] *Ibid.*; United States, Centers for Disease Control, "Update: Acquired Immunodeficiency Syndrome and Human Immunodeficiency Virus Infection Among Health-Care Workers" (1988), 37 MMWR 229. There are as yet no documented cases of occupationally acquired HIV infection in Canada: Canada, Federal Centre for AIDS, "Update—National Surveillance of Occupational Exposure to the Human Immunodeficiency Virus (HIV)" (October 31, 1991), at 1.

[129] Notwithstanding considerable efforts to enforce compliance with universal precautions in health care settings, a recent study found that many health care workers continue to recap needles, an activity that can easily result in a needle-stick injury. Recapping was related to inadequate knowledge, concerns about personal risk, forgetfulness, being "too busy" to follow universal precautions, and the misperception that recapping was a way to avoid a needle-stick injury. Efforts are needed to improve and supplement compliance with universal precautions. See Becker *et al.*, "Noncompliance with Universal Precautions Policy: Why Do Physicians and Nurses Recap Needles?" (1990), 18 Am. J. Infection Control 232.

[130] Bell, *supra*, note 125, at 119.

[131] *Ibid.*

The second alternative is the routine testing of patients. Because the risk of a needle-stick incident or mucous membrane exposure is greatest in the case of invasive surgery, many proposals have focused particularly on the testing of surgical patients. Studies show that a surgeon's risk of becoming HIV-infected when operating on an *infected* patient is between 1 in 130,000 and 1 in 4,500.[134] Some surgeons have argued that they have the "right to know" when they are operating on an infected patient.[135]

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[132] See Canada, Health and Welfare, *Recommendations for Prevention of HIV Transmission in Health-Care Settings*, Can. Diseases Wkly. Rep. (Supp.) (November, 1987). These recommendations should be in effect in any setting where exposure to blood is possible, including, for example, police and fire departments.

[133] The economic costs of universal precautions are not insignificant. One American study estimates that universal precautions cost U.S. hospitals $336 million in 1989. See Doebbeling and Wenzel, "The Direct Costs of Universal Precautions in a Teaching Hospital" (1990), 264 J.A.M.A. 2083.

The costs of HIV testing of all hospital patients would also be very considerable. The Ontario Hospital Association estimates that it would cost at least $72 million per year to perform hospital-wide testing for HIV in Ontario. See Ontario Hospital Association, *AIDS/HIV Infection: Guidelines and Information for Hospitals* (July, 1988), at 49 (hereinafter referred to as "OHA, *AIDS/HIV Infection*").

[134] Hagen, Meyer, and Pauker, "Routine Preoperative Screening for HIV: Does the Risk to the Surgeon Outweigh the Risk to the Patient?" (1988), 259 J.A.M.A. 1357-59.

[135] It is also possible that a health care worker may attempt to evoke the right to refuse unsafe work, as provided in s. 43(3) of the Ontario *Occupational Health and Safety Act*, R.S.O. 1990, c. O.1. In addition, the information would be useful if a treatment existed that, promptly administered, could either prevent or postpone infection or disease. Given that most medication may have some adverse effects, a health care worker will want to know whether the risk of infection from exposure was sufficient to outweigh the risks involved in the indicated treatment. It has been suggested that administering a treatment like zidovudine (AZT) prophylaxis, which has toxic side-effects, immediately after initial infection may slow or halt the progression of the infection. Recent clinical findings have cast considerable doubt upon this theory, however. No available treatment has demonstrated safety and efficacy in preventing infection, although of course it is possible that one could be developed. See Lange *et al.*, "Failure of Zidovudine Prophylaxis after Accidental Exposure to HIV-1" (1990), 322 New Eng. J. Med. 1375. The U.S. Public Health Service has declined to make a recommendation about the use of zidovudine as a prophylaxis, because human studies are inadequate to establish the efficacy or safety of such treatment: "Public Health Service Statement on Management of Occupational Exposure to Human Immunodeficiency Virus, Including Considerations Regarding Zidovudine Postexposure Use" (1990), 39 MMWR 1. The Ontario Hospital Association recommends that source patients should be tested for HIV only with their voluntary, specific, and informed consent, as in any other circumstance: OHA, *AIDS/HIV Infection*, *supra*, note 133.

There are numerous problems with testing patients on a routine basis. First, the knowledge of a patient's HIV status does not necessarily reduce the risk of transmission. In most of the cases of reported hospital transmission, the patient's HIV status was already known to the health care worker in question.[136] As noted earlier, a number of false negatives will also be identified under the available HIV antibody tests.[137] A false negative presents the likelihood that health care workers may develop a misplaced sense of security, which could lead to increased, rather than decreased, occupational risks if the test results, rather than universal precautions, are relied on. In the United States, despite policy statements by both the American Dental Association and the American Medical Association affirming the health care professional's ethical and legal duty to treat HIV-infected patients, reports of dentists and doctors who refuse to treat such patients remain disturbingly common.[138] Testing carries other risks for health care workers. Proposals to test patients are likely to trigger counter-demands that health care workers be tested. The patient may have an equally compelling "right to know" the HIV status of her doctor.[139]

The Ontario Hospital Association (OHA) has published guidelines to assist hospitals in caring for HIV-infected patients and ensuring a safe working environment.[140] The guidelines affirm the importance of universal precautions in the hospital setting and the necessity of obtaining voluntary, specific, and informed consent as a prerequisite to an HIV antibody test. The OHA notes the high economic, social, and ethical costs of involuntary testing and concludes that these costs cannot justify an uncertain and speculative benefit. A safe working environment in the health care setting is best achieved by universal precautions, not by universal or selective testing. The Commission believes that no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified with respect to patients in the health care setting. A safe working environment for health care workers can be effectively and efficiently secured only through adherence to the practice of universal precautions.

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[136] Brandt, Cleary, and Gostin, *supra*, note 125, at 133.

[137] See *supra*, ch. 1, sec. 1(d).

[138] American Civil Liberties Association, *supra*, note 66, at 31. See, also, Jonsen, "The Duty to Treat Patients with AIDS and HIV Infection", in Gostin (ed.), *AIDS and the Health Care System*, (1990), at 155. Some health care workers, like society as a whole, are terrified by AIDS and HIV infection. They feel that almost any measures to avoid infection, even highly costly and invasive procedures such as mandatory or compulsory testing, are justified. Protection against any variety of blood-borne infections, however, can only be assured through universal precautions. Blood is a potentially hazardous substance and must be treated accordingly—a change in practice that represents a fundamental shift in the prevailing wisdom. A number of other blood-borne pathogens exist, including HBV infection, a serious and occasionally fatal disease. Although the risks associated with blood have long been known, it is only with the identification of HIV that health care institutions have instituted appropriate risk-reducing procedures.

[139] See *infra*, this ch., sec. 4(b).

[140] OHA, *AIDS/HIV Infection*, *supra*, note 133.

(d) PREGNANT WOMEN

HIV infection poses special risks to women who are pregnant or considering pregnancy. Although estimates vary, the current evidence suggests that about 30 percent of HIV-infected mothers transmit HIV infection to their infants.[141] Many of these children become seriously ill and die within two years of their birth. It also appears that pregnancy may accelerate the progression of HIV infection in women who are seropositive but asymptomatic. For these reasons, it has been recommended that all pregnant women or women considering pregnancy be informed of the availability of voluntary HIV tests, especially in the event that a woman is at risk of HIV infection or comes from an area with a comparatively high seroprevalance rate.[142]

Although voluntary testing is appropriate in any case where there is a risk of infection, there has also been considerable discussion about whether HIV antibody testing should be a part of the routine blood tests generally performed on pregnant women. As in all situations where mandatory testing is considered, the utility of collecting the information must be carefully examined.[143]

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[141] Working Group on HIV Testing of Pregnant Women and Newborns, "HIV Infection, Pregnant Women, and Newborns" (1990), 264 J.A.M.A. 2416, at 2416.

See, also, Washington, D.C., Institute of Medicine, *HIV Screening of Pregnant Women and Newborns*, Hardy (ed.) (1991), at 18 (hereinafter referred to as "*HIV Screening of Pregnant Women and Newborns*").

[142] Gunderson, Mayo, and Rhame, *supra*, note 100, at 163. See, also, *HIV Screening of Pregnant Women and Newborns, supra*, note 141, at 3-4, where the Committee recommends "voluntary HIV screening (with specific informed consent) for all pregnant women in high-prevalence areas".

[143] In the ideal case, the information would be useful in either preventing perinatal transmission of HIV infection or treating the infant to prevent infection or retard the development of disease. A woman who knows she is HIV-infected can make informed decisions about family planning: Miller, Turner, and Moses, *supra*, note 101, at 101-02. In addition, such information may be important for mothers considering breastfeeding. Several cases of postnatal HIV transmission to infants through breastfeeding have been documented. The availability of safe and effective alternatives to breast milk, in the form of human milk substitutes, prompted the current recommendation in the United States that HIV-infected women be advised against breastfeeding to avoid postnatal transmission to infants who may not already be infected: *HIV Screening of Pregnant Women and Newborns, supra*, note 141, at 38, *n.* 4. See, also, United States, Centers for Disease Control, "Recommendations for Assisting in the Prevention of Perinatal Transmission of

Although no treatment can prevent perinatal transmission, some therapeutic interventions have been developed for symptomatic HIV-infected children, including AZT therapy and prophylactic therapy for certain opportunistic infections.[144] Although there is some hope that these treatments may be effective in asymptomatic HIV-infected newborns, there is also uncertainty about the benefits and risks of early therapeutic intervention.[145] Moreover, the HIV antibody test used at present fails to differentiate infected neonates from uninfected. All infants born to HIV-infected mothers carry passively acquired maternal antibodies which may persist for up to fifteen months, although approximately two-thirds of such infants are uninfected. Because of this uncertainty, even if early therapeutic intervention had some proven efficacy, it would still be impossible to determine which infants might be in need of therapy.[146] Because no available treatment can prevent perinatal transmission or effectively treat asymptomatic HIV infants, the testing of pregnant women would not significantly further any public health objective to prevent the spread of HIV. For these reasons the mandatory or routine testing of pregnant women has not been systematically introduced in either Canada or the United States. Nonetheless, the situation could change if an effective treatment is developed to prevent perinatal transmission or if an effective early intervention therapy is developed for asymptomatic HIV-infected infants. The Commission believes that no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified respecting pregnant women. In areas where the seroprevalence rate is particularly high, it may be appropriate to make particular efforts to inform all women of childbearing age of the potential risk of perinatal transmission and the free availability of voluntary HIV antibody tests.

Human T-lymphotropic Virus Type III/lymphadenopathy-associated Virus and Acquired Immunodeficiency Syndrome" (1985), 34 MMWR 721.

[144] *HIV Screening of Pregnant Women and Newborns, supra*, note 141, at 25-26. See, also, United States, Centers for Disease Control, "Guidelines For Prophylaxis Against *Pneumocystis Carinii* Pneumonia for Children with Human Immunodeficiency Virus" (1991), 40 MMWR 1.

[145] *HIV Screening of Pregnant Women and Newborns, supra*, note 141, at 25-26.

[146] *Ibid.*, at 30. A definitive diagnostic test for neonatal HIV infection might change the current situation, however. A valid, reliable test would diminish the risk of exposing uninfected infants to potentially toxic therapy: *ibid.*

(e) SEX WORKERS

In a 1988 British Columbia decision, *R. v. G.D.M.*,[147] a male prostitute was convicted of soliciting and placed on probation for six months. As a condition of probation, he was required to furnish a certificate once a month to his youth worker stating that he had been tested for HIV and other venereal diseases.[148] The test results remain confidential between the accused and his physician. The Court ordered the condition on the grounds that it tended to promote the good conduct of the offender and to prevent the commission of further offences.[149] The Court reasoned that an HIV test would "bring home" to the young person that he was at a high risk of becoming HIV-infected as a result of his "way of life" whether "he utilizes 'safe' practices or not". The Court also held that the requirement of a test did not violate the unreasonable search and seizure provisions of section 8 of the Charter, because the HIV test was reasonable and rationally related to securing the good conduct of the offender.[150] Finally, the Court concluded that the condition was primarily designed for the rehabilitation or deterrence of the offender rather than for the protection of public health, and noted that if the condition was solely for public health reasons, "the order would not be justified".[151]

Almost one-half of the states in the United States have enacted legislation that provides for some form of mandatory or compulsory HIV-related testing of persons convicted of prostitution.[152] Florida requires women convicted of prostitution to undergo testing for a variety of STDs, including HIV infection; women who are found to be infected must submit to treatment and counselling as a condition of their release.[153] In California persons convicted of prostitution are required to submit to an HIV test; if they are found to be infected, any subsequent prostitution charges will be treated as felonies.[154] In Illinois persons convicted of sex-related offences, which are defined to include both prostitution and patronizing a prostitute, are required to undergo testing for HIV.[155] In Nevada, any person arrested for engaging in prostitution except in a house of licensed prostitution (where prostitutes are regularly tested for HIV infection) must submit to an HIV test.[156]

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[147] (1988), 22 B.C.L.R. (2d) 390 (Co. Ct.).

[148] *Young Offenders Act*, R.S.C. 1985, c. Y-1, s. 23(2)(*g*), includes language very similar to that of s. 737(2)(*h*) of the *Criminal Code*, *supra*, note 108, and provides that a court may issue a probation order requiring that the young person "comply with such other reasonable conditions set out in the order as the court considers desirable, including conditions for securing the good conduct of the young person and for preventing the commission by the young person of other offences".

[149] *R. v. G.D.M.*, *supra*, note 147, at 395.

[150] *Ibid.*, at 394.

[151] *Ibid.*, at 396.

[152] See Gostin and Ziegler, "A Review of AIDS-related Legislative and Regulatory Policy in the United States" (1987), 15 L., Med. and Health Care 5.

[153] *Ibid.*

In addition to legislation that targets the practice of prostitution, several states have also enacted criminal legislation that imposes penalties specifically on HIV-infected persons who expose other individuals to the virus.[157] Although there is no such specific legislation in the *Criminal Code*, the common nuisance provisions of the Code have been used in at least one case to convict an HIV-infected person who had engaged in unprotected sexual intercourse.[158]

Despite these legislative enactments in the United States, and in at least one judicial decision in Canada,[159] it is not clear that mandatory testing of sex workers can help deter high-risk activity. The effect of these laws has been to drive prostitution underground and limit the areas in which it is practised.[160] Similarly, it is not clear that a female sex worker's clients are at a significantly increased risk of infection. A large percentage of female prostitutes report using condoms with their clients, which reduces the risk of infection.[161] Further, the risk of female-to-male transmission is lower than the risk of male-to-female transmission.[162] This might explain why the reported rate of infection among male clients of female prostitutes is low.[163] It also suggests that female prostitution, by itself, is not a significant factor in the transmission of HIV.

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[154] In *Love v. The People*, U.S.C.A., December 28, 1990 (unreported), the Court held that "testing has been seen to have a preventive aspect in the spread of [HIV]" and that the subsequent penalty enhancement for continued violation of the section by infected persons is "a means to deter acts known to spread the disease". Likewise, the Court held that the taking of blood for these purposes does not violate the Fourth Amendment (unreasonable search and seizure) as the intrusion is "minimal" and furthers a legitimate governmental interest.

[155] Ill. Ann. Stat., ch. 38, §1005-5-3(g) (Smith-Hurd 1989).

[156] Nev. Rev. Stat. Ann., §§201.354, 201.356 (Mitchie 1988).

[157] Gostin and Ziegler, *supra*, note 152, at 12.

[158] *R. v. Summer* (1989), 98 A.R. 191 (Alta. Prov. Ct.); aff'd (1989), 69 Alta. L.R. (2d) 303, 73 C.R. (3d) 32 (C.A.). Section 180 of the *Criminal Code*, *supra*, note 108, provides that a person commits a common nuisance where he "endangers the lives, safety or health of the public".

[159] *R. v. G.D.M.*, *supra*, note 147.

[160] National Research Council, in Miller, Turner, and Moses, *supra*, note 101, at 278.

[161] *Ibid.*, at 260. One study found that as many as 80 percent of prostitutes surveyed reported at least the occasional use of condoms.

[162] See, for example, *HIV Screening of Pregnant Women and Newborns*, *supra*, note 141.

In the absence of any effective treatment for HIV infection, it is not clear how involuntary testing could be useful in preventing HIV transmission in the sex industry. Unless Canadians were willing to consider isolating indefinitely or otherwise restricting all infected sex workers – measures that would encourage prostitutes and others at risk to avoid HIV-related testing and other help-seeking alternatives – little could be done with the information. In short, for both the client and the sex worker the Commission believes the risk of transmission is best addressed by targeted education efforts and programs designed to encourage risk-reducing behaviour, including information about the use of condoms and clean needles.[164] No exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified with respect to male or female sex workers.

(f) INMATES IN PROVINCIAL CORRECTIONAL FACILITIES

The mandatory or compulsory testing of inmates in correctional facilities and prisons has been debated since the HIV antibody test was developed in 1985. Although the involuntary testing of inmates has not been adopted in Canada,[165] it has been introduced in much of the United States. According to a 1988 study by the American Civil Liberties Association National Prison

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[163] For example, as of 1989, only 0.08 percent of the total number of adult AIDS cases in the United States were likely acquired through contact with female sex workers (33 cases out of 41,770): see, generally, National Research Council, "Interventions for Female Prostitutes", in Miller, Turner, and Moses, *supra*, note 101, at 262. No similar figure is available for the clients of male sex workers.

[164] In fact, the introduction of mandatory testing of sex workers has been shown to reduce the use of condoms, because clients may erroneously believe that testing has eliminated any risk of infection: *ibid.*, at 280.

[165] Mandatory testing is not currently in force in any provincial or federal prison in Canada. This report will focus primarily on the current practice and policy in the correctional facilities operated by the Ontario Ministry of Correctional Services.

The *Ministry of Correctional Services Act*, R.S.O. 1990, c. M.22, does not provide any express authority for the Ministry to introduce any program such as the mandatory testing of all inmates, although it is possible that the Ministry could attempt to issue a regulation under s. 60(*e*), which permits regulations respecting the "treatment ... discipline, [and] control" of inmates. It is more likely that any decision to implement mandatory testing would be made by the local medical officer of health who must be notified by the physician of the correctional institute about any person who is infected with a communicable disease: HPPA, s. 37.

Project, thirteen states test all new inmates.[166] The Federal Bureau of Prisons in the United States also tests certain classes of inmates, including a random selection of 5 percent of incoming inmates, all inmates who are involved in community activities, and all inmates at least sixty days before they are discharged.[167] American prisons that test inmates usually have some form of case-by-case segregation policy for those found to be HIV-infected. Some prisons segregate only those who have developed symptomatic HIV-related disease.[168] Only a very small number of prisons segregate all HIV-infected inmates.[169]

Those who argue in defence of involuntary testing focus on the prevention of the spread of HIV infection contracted through injection drug use, through sexual assault, or from inmate to employee through exposure to the blood or bodily fluids of an HIV-infected inmate.[170] It is not clear, however, how the identification of HIV-infected inmates will significantly improve efforts to prevent the spread of infection in the facility.

The *Communicable Diseases Policy* issued by the Ontario Ministry of Correctional Services[171] endorses an HIV prevention program that focuses on universal precautions and public health education programs directed towards the special needs of inmates and staff as the primary means to reduce the risk of transmission in correctional facilities. In the opinion of the Ministry, the mandatory testing of inmates is "neither legally permissible nor operationally practical or possible and is not necessary at this time".[172]

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[166] See Moss, "AIDS in Prison—To Test or Not?" ABA Journal (January, 1989).

[167] Gunderson, Mayo, and Rhame, *supra*, note 100, at 205.

[168] Moss, *supra*, note 166.

[169] See Pappas, "In Prison with AIDS: The Constitutionality of Mass Screening and Segregation Policies", [1988] 1 U. Ill. L. Rev. 151, at 185.

[170] The risk of infection with respect to employees of correctional facilities is much smaller than is the case with health care workers, since employees in correctional facilities are less likely to come into extensive contact with an inmate's blood or bodily fluids. The use of universal precautions in correctional facilities will further reduce the risk of infection. The prevention of the spread of infection between inmates is a more complicated matter, since the inmate population probably has a comparatively higher seroprevalence rate owing to the apparently widespread sharing of needles and high-risk sexual activity. See, for example, Martin, "Shared Needles Put Prisoners at AIDS Risk", *The Globe and Mail*, Toronto (November 4, 1991) A5, wherein a John Howard Society official stated that two studies in Quebec conducted in the late 1980s found that 7 percent of inmates in federal penitentiaries had contracted HIV. On the basis of the studies researchers estimated that 935 of more than 13,000 federal inmates may be HIV-infected.

[171] April, 1989.

[172] *Ibid.*, at 5. Although the Ministry policy statement does not detail the grounds upon which testing may not be permitted at law, it appears likely that the Ministry is referring either to the provisions of the Ontario *Human Rights Code* or to the Charter, both of which

Instead, voluntary testing with specific and informed consent is made available where it is clinically indicated or requested. As a rule, HIV-infected inmates are not segregated from the inmate population unless their medical condition requires that they be placed in a special needs unit.

Although the Ministry has rejected mandatory or compulsory HIV testing as part of its prevention program, it is not clear that its current program is optimally effective in preventing the spread of HIV infection in correctional facilities. The Ministry's long-standing policy prohibits all sexual activity in the correctional system in order to provide a "safe and secure" environment and reduce the spread of sexually transmitted diseases.[173] As a result of this policy, the Ministry has consistently refused to distribute condoms in its facilities, notwithstanding that the use of condoms has been demonstrated to reduce significantly the risk of transmission of many STDs, including HIV infection.[174]

Similarly, the Ministry restricts the distribution of bleach. Although bleach is a toxic substance, it was previously available in some correctional facilities for general cleaning purposes, and no security problems were reported. A bleach solution can be used to clean injection equipment and its distribution can reduce the risks of HIV transmission associated with injection drug use. While the distribution of condoms in correctional facilities has been much debated in Canada and the United States, in November, 1991 the Canadian federal government announced that condoms would be made available to inmates to curb the spread of HIV infection in federal penitentiaries.[175] However, a proposal to distribute clean needles to inmates in those institutions was rejected.[176] Given the federal initiative to provide condoms to inmates in penitentiaries and the risk of HIV transmission within correctional facilities resulting from high-risk behaviour, we believe that it would be appropriate to make condoms and bleach

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would generally prohibit provincial correctional authorities from discriminating against inmates on the basis of a physical disability. Absent a rational public health objective, the mandatory testing of inmates could constitute such discrimination. The provisions of the Charter (s. 9 or s. 12) that deal with arbitrary detention and cruel and unusual punishment, may also be relevant. See, also, MacKay, "Inmates' Rights: Lost in the Maze of Prison Bureaucracy?" (1988), 11 Dalhousie L. J. 698.

[173] *Communicable Diseases Policy*, *supra*, note 171, at 8.

[174] *Ibid.*, at 3. The Ministry has also argued that condoms could be used to disrupt security—that is, they could be used as ligatures (as an aid to suicide or as potential weapons) or to jam locks or smuggle drugs.

[175] Vienneau, "Inmates to Get Condoms in Effort to Curb AIDS", *The Toronto Star* (November 1, 1991) A13. The Alberta government also plans to distribute condoms to inmates in provincial facilities: "Alberta to Provide Condoms in Jails", *The Toronto Star* (November 14, 1991) A14.

[176] *Ibid.* See, also, "Shared Needles Put Prisoners at AIDS Risk", *supra*, note 170.

available to inmates as part of a targeted public health education program in Ontario's correctional facilities. The Commission concludes that no exception to a general rule requiring voluntary, specific, and informed consent for all HIV-related testing is justified respecting inmates in correctional institutions. Targeted HIV education campaigns and programs directed towards the special needs of inmates and correctional institution officials, including the availability of condoms and bleach, are the best means currently available to reduce transmission within this setting.*

(g) APPLICANTS FOR HEALTH OR LIFE INSURANCE

In the United States,[177] the imposition of mandatory HIV testing on applicants for health and life insurance has been intensely debated. Because current scientific evidence continues to confirm that HIV infection is an accurate predictor of the eventual development of a costly and probably fatal illness,[178] insurance companies have a compelling incentive to avoid the high costs associated with HIV infection,[179] and have been using the HIV antibody test almost since its inception to screen out high-risk applicants.

The debate is particularly serious in the United States, which has no comprehensive national health insurance program. The federal Medicare program covers all people over the age of sixty-five. Medicaid, the other major government program, covers only persons whose income falls below a certain level as set by individual states. Outside these two government programs, there are two types of private insurance: employee group insurance and individual insurance. Group insurance covers the majority of Americans: 85 to 90 percent of all private health insurance policies are group policies. In most cases, all members of an employee group are eligible for group coverage without any medical inquiry. HIV-related tests are usually performed only on applicants for individual policies, the remaining 10 to 15 percent of the private health insurance market, which comprises approximately 15 million people.[180]

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* Statement of Dissent by Commissioner Margaret A. Ross, concurred in by Commissioner Earl A. Cherniak, Q.C.

I am compelled to make a distinction between the types of behaviour being addressed in this discussion. Intravenous drug use is illegal behaviour whether it occurs inside or outside a correctional facility. I am not prepared to endorse a publicly-sponsored initiative which has the effect of legitimating an illegal activity. In addition, there has not been sufficient analysis of other potential harmful effects of making bleach or clean needles available to inmates. I would encourage comprehensive efforts by correction authorities to parallel the public education initiatives which attempt to address the risks associated with intravenous drug use which are currently underway outside of correctional facilities.

[177] See, for example, Schatz, "The AIDS Insurance Crisis: Underwriting or Overreaching?" (1987), 100 Harv. L. Rev. 1782; Clifford and Iuculano, "AIDS and Insurance: The Rationale for AIDS-Related Testing" (1987), 100 Harv. L. Rev. 1806; and Stone, "The Rhetoric of Insurance Law: The Debate over AIDS Testing" (1990), 15 L. & Soc. Inquiry 385.

[178] See *supra*, ch. 1.

[179] The estimated costs of caring for HIV-infected persons vary widely, and they can be expected to change dramatically as new treatments and community-based care programs are developed. Past studies have indicated that the estimated lifetime costs of hospitalization for people with AIDS to be $60,000 to $75,000 (U.S.) per patient: see Scitovsky and Rice, "Estimates of the Direct and Indirect Costs of AIDS in the United States, 1985, 1986, and 1991," (1987), 102 Pub. Health R. 5.

In Canada, where all citizens are entitled to health care, regardless of their medical condition, the debate has largely focused on the testing of applicants for life insurance.[181] Unlike health insurance, whose primary purpose is to provide access to crucial medical services, the purpose of life insurance is to provide a degree of financial security to the dependents of policyholders or, in the business context, to protect the business assets of partners when one partner dies. Occasionally, life insurance is also a prerequisite for certain jobs, such as "key person coverage", or for obtaining credit, such as mortgage life insurance.[182] As a result, rules or practices that restrict people's access to life insurance will limit their ability to provide financial security for their dependants, and may in some circumstances limit their ability to hold certain jobs or obtain credit.

A few states in the United States have attempted to prohibit insurance companies from using the results of an HIV test to determine insurability for either health or life insurance, over the protests of the insurance industry. In 1985 California enacted legislation that broadly prohibited insurance companies from using an HIV test to determine insurability.[183] In 1988 the legislation was amended to allow testing for life and disability insurance, but not for health insurance.[184] In New York, the State Superintendent of Insurance promulgated a regulation in 1987 that banned insurers from considering HIV test results in determining insurability. (This regulation was later struck down by the Appellate Division of the Supreme Court of New York as *ultra vires* the authority of the Superintendent.)[185] In 1986 the District of Columbia enacted legislation prohibiting the use of HIV tests for insurance purposes.[186] This legislation attracted the unfavourable attention of Congress, which has a degree of legislative authority over the District. As a result, the District's city council was forced by Congress in 1989 to repeal its HIV testing prohibitions.[187] In short, U.S. attempts to restrict HIV testing by insurers have met with comparatively little success.

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[180] Stone, *supra*, note 177, at 388-90.

[181] Supplementary health insurance and long-term disability insurance is also widely available in Canada; however, the large majority of these programs are offered by employers to all their employees without any requirement of medical evidence of individual insurability. In other words, HIV testing is not required for these supplementary health insurance programs: communication with C. Black, vice-president, insurance operations, Canadian Life and Health Insurance Association (March 7, 1991).

[182] Stone, *supra*, note 177, at 390.

[183] California Health and Safety Code, §199.21(f) (West Supp. 1990), as en. by Stats. 1985, c. 22, §1, am. by Stats. 1985, c. 23, §1.5; Stats 1987, c. 1391, §1.

[184] California Insurance Code, §799.02 (West 1991).

Ontario has no laws that specifically prohibit insurance companies from using HIV tests to determine insurability. It is the widespread practice of insurers in Ontario, as in the United States, to require HIV tests of all applicants for life insurance policies.[188] This practice is vigorously defended by the insurance industry, which argues that HIV testing is a legitimate underwriting practice consistent with industry treatment of other similar conditions.[189]

Insurance underwriting is the process by which an insurer determines whether and on what basis it will insure an applicant. The underwriter's primary goal is the accurate prediction of future mortality and morbidity costs. Insurers establish premiums at a level consistent with the risk represented by each individual policyholder. To do this, insurers create classifications to determine risk assessments, such as age, health history, occupation, and the use of alcohol and tobacco. Without these classifications, insurers claim it is difficult to assess accurately the risk presented by any given applicant.[190] This will result in rising insurance premiums for all applicants, arguably unfairly raising the cost of insurance for persons who actually have a lower risk assessment. In the most extreme circumstance, an inability to predict risk accurately could ultimately threaten the insurer's solvency.

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[185] *Health Insurance Association of America v. Corcoran*, 551 N.Y.S. 2d 615 (A.D. 3 Dept., 1990). The Court held that the use of HIV testing was a sound underwriting practice sanctioned by the basic principles of insurance law and regulation, and that the insurance department lacked the legal authority to prohibit it. A similar regulation promulgated by the State Insurance Commissioner in Massachusetts was likewise struck down by the courts.

[186] D.C. Code Ann., §35-277 (West 1987).

[187] *Prohibition of Discrimination in the Provision of Insurance Amendment Act of 1988*, Vol. 7, D.C. Reg. p. 208 (1988).

[188] See, generally, Black, *AIDS and Insurance*, policy paper issued by the Canadian Life and Health Insurance Association (December, 1986). See, also, Clifford and Iuculano, *supra*, note 177, at 1812-21. Although HIV testing is not generally performed on applicants for life insurance coverage of under $100,000, all applicants are usually required to state whether they have any immune system abnormality or have sought medical advice or treatment in the preceding two years. As a result, applicants who know they are HIV-infected would be denied insurance.

[189] *Ibid.*

[190] *Ibid.*

The importance of risk-related information is recognized by the *Insurance Act* of Ontario,[191] which provides that an applicant "shall...disclose to the insurer in the application, on a medical examination, if any, and in any written statements or answers furnished as evidence of insurability, every fact within his knowledge that is material to the insurance and is not so disclosed by the other". A misrepresentation or a failure to disclose will render the contract voidable by the insurer.[192] The right of insurers to classify applicants on the basis of evidence of insurability is specifically preserved by the Ontario *Human Rights Code*, which provides that the right to equal treatment with respect to services, and the right to contract on equal terms as provided in sections 1 through 3 of the Code, is not infringed where a contract of life, sickness, or disability insurance "makes a distinction, exclusion or preference on reasonable and *bona fide* grounds because of age, sex, marital status, family status or handicap".[193]

In 1988 the New Brunswick Human Rights Commission considered whether an insurer could refuse to sell a guaranteed issue life insurance policy to HIV-infected persons.[194] Such a policy is usually issued to any person regardless of his or her medical history or condition. To protect insurers from the costs of issuing policies to high-risk individuals, the guaranteed issue policy provides only limited death benefits. During the first two years of the policy in question, full death benefits were to be paid only in the event of accidental death. Any other cause of death would result in death benefits equal to the premiums paid, with interest. Although these policies are usually issued to any person without any evidence of insurability, the insurer in question wanted to exclude persons who were already aware that they were HIV-infected. The insurer did not propose to test applicants.

The Commission held that the exclusion of HIV-infected persons did not constitute a *bona fide* qualification under the New Brunswick *Human*

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[191] R.S.O. 1990. c. I.8, s. 183(1).

[192] *Ibid.*, s. 183(2).

[193] Code, s. 21.

[194] *Blue Cross Life Insurance Co. of Canada* (October 18, 1988). The Blue Cross Insurance Company of Canada, pursuant to s. 5(2) of the New Brunswick *Human Rights Act*, R.S.N.B. 1973, c. H-11, as am. by 1976, c. 31, s. 2; 1985, c. 30, s. 7(*b*), made an application to the Commission to determine whether the refusal of Blue Cross to sell a certain life insurance policy to persons who have tested positive for HIV infection was permissible under the provisions of the Act. The decision turned on whether or not excluding such persons constituted a *bona fide* qualification under the Act.

Rights Act, which otherwise would permit differential treatment by insurers.[195] The Commission held that the exclusion of only HIV-infected applicants unfairly stigmatizes the disease; moreover, public health attempts to reduce the spread of HIV infection could be impaired if people at risk of infection were afraid to request an HIV test, knowing that the test results might later be used to deny them life insurance.

Insurers gather information relevant in making a risk assessment. This means that high-risk persons, such as those suffering or likely to suffer from any number of chronic or potentially fatal illnesses, will be denied life insurance. On this basis there is no compelling reason to treat HIV infection any differently from other diseases or factors, such as old age, smoking, or a history of heart disease, on the basis of which a life insurer might deny coverage to an applicant. Although there are some risk-related classifications that are impermissible for broader social reasons, such as sexual orientation, it is not clear that HIV infection should be entitled to a similar exception.

Although section 22 of the Ontario *Human Rights Code* expressly permits insurers to refuse contracts of insurance to persons with disabilities on reasonable and *bona fide* grounds, section 17(1) of the Code also creates a general duty to accommodate persons with physical disabilities. Section 17(1) states that the rights made available to physically disabled persons under the Code are "not infringed for the reason only that the person is incapable of performing or fulfilling the essential duties or requirements attending the exercise of the right". As a result, employers or service providers may discriminate against a physically disabled person if the disability prevents her from performing an essential aspect of the job or fulfilling some essential requirement of the service. This provision is qualified by section 17(2), which creates a general duty to accommodate the physically disabled, unless it is established that "the needs of the [physically disabled] person cannot be accommodated without undue hardship on the person responsible for accommodating those needs, considering the cost, outside sources of funding, if any, and health and safety requirements, if any".

It is the stated practice of Canadian insurers that all insurance applicants are to be informed that an HIV test will be done as part of their medical examination.[196] As in the case of blood donations, the applicant should be given adequate information about the nature and purpose of an HIV test. Although it appears that the majority of insurance companies inform applicants that an HIV test will be performed, it is not clear whether this is the uniform practice of all insurance companies. An action in battery, negligence, breach of contract, and breach of fiduciary duty has been brought against at least one insurance company for allegedly performing an HIV test on two life insurance applicants without their knowledge or consent.[197] This allegation not only raises the issue of potential legal liability, but is inconsistent with the value placed on individual autonomy and informed consent in medical treatment.[198]

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[195] *Blue Cross Life Insurance Co. of Canada*, *supra*, note 194.

[196] See Canadian Life and Health Association Inc., *Guidelines with Respect to AIDS for the Sale and Underwriting of Life and Health Insurance* (November 10, 1987). See, also, *supra*, this ch., sec. 1(b), for a discussion of the importance of informed consent.

Insurers who obtain HIV-related information must be required to rigorously maintain the confidentiality of that information. The industry pledges to protect this confidentiality,[199] although insurers are required to report the information to the provincial medical officer of health.[200] The scope of the insurer's liability for wrongful breach of confidentiality and the applicant's effective ability to enforce this duty of care are unclear. It may be appropriate to require the industry to monitor continually its efforts to protect the confidentiality of medical information. The Commission concludes that no insurer should be permitted to require an applicant for insurance coverage to be tested for HIV without first informing the applicant that an HIV-related test will be performed and providing the applicant with adequate information about the nature and purpose of an HIV-related test. We believe that insurers should be required to take all reasonable steps to safeguard the confidentiality of all HIV-related personal information they acquire.

4. TESTING IN THE WORKPLACE: PUBLIC SAFETY AND PUBLIC HEALTH

Because HIV transmission is sexual or blood-borne and not casual, there is no effective risk of transmission in the majority of workplaces. As knowledge about the limited transmissibility of HIV infection has increased, anxiety about transmission in the workplace has correspondingly decreased. The development of fairly comprehensive legal protections for HIV-infected persons, notably the remedies available under the Ontario *Human Rights Code* and the *Canadian Human Rights Act*,[201] has also been extremely important in ensuring that both private and public employers do not adopt policies that irrationally discriminate against HIV-infected workers.

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[197] *John A. v. Canada Life Assurance Co.* (1989), 35 C.P.C. (2d) 6 (Ont. H.C.J.).

[198] *Supra*, this ch., sec. 1(b).

[199] See Canadian Life and Health Insurance Association Inc., *Right to Privacy Guidelines* (1980).

[200] *Infra*, ch. 3.

[201] *Supra*, note 75.

The systematic introduction of mandatory HIV testing of prospective or current employees has not been reported anywhere in Ontario or Canada, and it is clear that the provisions of the Ontario Code generally prohibits the introduction of mandatory testing in workplaces.[202] Although mandatory HIV testing has not yet been systematically introduced in any workplace in Ontario, the topic has been seriously considered in at least two cases. The first of these deals with the protection of public safety. The second (and much more difficult) case deals with the objective of protecting public health.

(a) PUBLIC SAFETY: HIV-RELATED NEUROPSYCHOLOGICAL IMPAIRMENT?

When a 1987 study suggested that HIV infection may be accompanied by slight neuropsychological impairment as measured by neuropsychological tests,[203] mandatory testing was considered for some workers whose duties involved public safety, such as pilots and air traffic controllers. More recent research, conducted on larger population samples and larger control groups, has challenged the findings of the 1987 study.[204] In 1990 the World Health Organization also published a report on its most recent consultation on HIV-related neuropsychological impairment, and concluded that otherwise healthy HIV-infected individuals are not more likely to present a clinically significant cognitive impairment than uninfected individuals; as a result "there is, at the present time, no justification for HIV-1 serological screening of asymptomatic people as a strategy for detecting such impairment in the interest of public safety".[205]

Since the mandatory HIV-related testing of employees is not rationally related to the protection of public safety, an employee's HIV status cannot reasonably be considered a *bona fide* occupational qualification for employment in positions that involve public safety.[206] The Commission believes that no exception to a general rule requiring voluntary, specific, and informed consent is justified respecting employees for the protection of public safety.

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[202] *Supra*, this ch., sec. 2(b).

[203] Grant *et al.*, "Evidence for Early Central Nervous System Involvement in the Acquired Immunodeficiency Syndrome (AIDS) and other Human Immunodeficiency Virus (HIV) Infections" (1987), 107 Annals Internal Med. 828. The study concluded that there were cognitive deficiencies in a group of sixteen HIV-infected but asymptomatic individuals.

[204] See, for example, Tross *et al.*, "Neuropsychological Characterization of the AIDS Dementia Complex: A Preliminary Report" (1988), 2 AIDS 81; and Selnes *et al.*, "HIV-1 Infection: No Evidence of Cognitive Decline during the Asymptomatic Stages" (1990), 40 Neurology 204.

[205] "World Health Organization Consultation on the Neuropsychiatric Aspects of HIV-1 Infection" (1990), 4 AIDS 935, at 936.

(b) PUBLIC HEALTH: HIV TRANSMISSION IN THE HEALTH CARE SETTING?

Mandatory testing has also been proposed for public health purposes – that is, to prevent HIV transmission in the workplace. As we have noted, the risk of transmission is only relevant in a workplace that may involve exposure to blood or bodily fluids, and proposals for testing have therefore focused primarily on the health care setting. In particular, testing of some or all health care workers has been proposed to reduce any risk that HIV-infected health care workers may present to patients. Because some health care workers, particularly dentists and surgeons, frequently perform highly invasive procedures, and occasionally may sustain a skin puncture whereby some of their blood might enter the patient's body, it has been suggested that such procedures may in some circumstances result in the transmission of HIV from an infected health care worker to a patient. Until recently, however, no case of HIV transmission from an infected health care worker to a patient had been established.

In July, 1990, the American Centers for Disease Control (CDC) reported the first identified case of possible transmission of HIV to a patient from an HIV-infected health care worker. Transmission appeared to occur during an invasive procedure performed by Dr. D. Acer, a dentist who had AIDS.[207] In January, 1991, the CDC reported possible HIV transmission during dental procedures to two other patients of the same dentist.[208] In June, 1991, two additional cases were identified, bringing to five the number of patients possibly infected by this dentist.[209]

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[206] Both the *Canadian Human Rights Act*, *supra*, note 75, and the Ontario *Human Rights Code* provide that the testing or exclusion of an HIV-infected employee would not constitute discrimination if it is based on a *bona fide* occupational qualification. *Supra*, this ch., sec. 2(b).

[207] United States, Centers for Disease Control, "Possible Transmission of Human Immunodeficiency Virus to a Patient during an Invasive Dental Procedure" (1990), 39 MMWR 489.

[208] United States, Centers for Disease Control, "Update: Transmission of HIV Infection during an Invasive Dental Procedure – Florida" (1991), 40 MMWR 21.

[209] American Health Consultants, "Unreported Findings Shed New Light on HIV Dental Case" (1991), 18 Hospital Infection Control 85. See, also, Hardie and Samaranayake, "A Critique of HIV Transmission during Dental Treatment" (1991), 57 Journal 487.

The way in which the patients became infected has not yet been and may never be conclusively established.[210] Experts remain puzzled by the Florida cases, however, since thousands of former patients of HIV-infected health care workers have been tested in the United States to determine whether any of them might have become infected as a result of an invasive procedure or other contact with the HIV-infected worker. No cases of transmission were found.[211] The Florida case has nonetheless provoked considerable public anxiety. The debate has focused on the question whether health care workers should be required to undergo HIV testing with the objective of excluding infected workers from the practice of their profession, or at least excluding them from the practice of certain invasive procedures.[212]

Opponents of testing cite numerous studies suggesting that the risk of transmission from an infected health care worker to a patient is extremely low, even in the case of invasive procedures.[213] Mandatory testing and exclusion have never been adopted with respect to other more easily transmitted and even occasionally fatal infectious diseases, such as hepatitis-B.[214] Instead, infection control procedures for health care workers with chronic hepatitis-B infection have focused on a strict adherence to barrier precautions and other infection control techniques.

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[210] *Ibid.* Although barrier precautions were reportedly used by Dr. Acer, his techniques were not always consistent or in compliance with recommendations. For example, reports indicate that Dr. Acer sometimes washed his gloves instead of changing them for each new patient. It also appears that the dentist treated a number of HIV-infected patients in his practice. It is possible, therefore, that transmission may have occurred from one HIV-infected patient to another patient as a result of inadequate infection control measures.

[211] See, for example, Mishu *et al.*, "A Surgeon with AIDS: Lack of Evidence of Transmission to Patients" (1990), 264 J.A.M.A. 467, where 2,160 patients of a general surgeon who died of AIDS were investigated. There was no evidence of HIV transmission to any of the surgeon's former patients. Dr. William Roper, director of the American Centers for Disease Control, has confirmed that the CDC are aware of at least 60 cases of health care workers who are HIV-infected. Tests of 8,000 of their patients found none had been infected by a health care worker: "Experts Oppose AIDS Tests for Doctors" *The New York Times* (September 20, 1991) A11.

[212] See, for example, Gostin, "The HIV-Infected Health Care Professional: Public Policy, Discrimination, and Patient Safety" (1990), 18 L., Med., & Health Care 303; and Barnes *et al.*, "The HIV-Infected Health Care Professional: Employment Policies and Public Health" (1990), 18 L., Med., & Health Care 311.

[213] See, generally, Barnes *et al.*, *ibid.*

[214] Hepatitis-B is also significantly more infectious than HIV infection. For example, the risk of transmission of hepatitis-B infection from a patient to a health care worker by accidental injury, such as a needle-stick, is much greater than HIV infection. Ongoing studies indicate that the risk of transmission of HIV if such an injury occurs is in the range of 1 in 1000 if treating an HIV-infected patient. The comparative risk with hepatitis B is 1 in 4. See Read, "Human Immunodeficiency Virus (HIV-1) Infection", in Canadian Bar Association – Ontario, *Health Law: Unfolding Issues of Today and Tomorrow* (May 10, 1989).

Proponents of testing argue that although the risk of transmission is very low, it is within such a range that public health policy should urge that certain precautions be taken.[215] In contrast to hepatitis-B, the consequences of HIV infection are uniformly serious, if not fatal, thereby justifying more costly measures to prevent infection. Further, an effective public health response need not necessarily involve mandatory testing and exclusion. Instead, health care professions could impose upon themselves a professional obligation to monitor their HIV status regularly and report any finding of an HIV-positive serological status to their employers, thus triggering appropriate infection control measures and avoiding any highly invasive procedures.

In response to reports of HIV transmission in the case of Dr. Acer, in July, 1991, the United States Centers for Disease Control finally issued long-awaited guidelines for HIV-infected health care workers.[216] The guidelines contain six recommendations:

(1) All health care workers should adhere to universal precautions in the health care setting, including the use of protective barriers and the disinfection and sterilization of reusable devices used in invasive procedures.

(2) Currently available data provide no basis to restrict the practice of health care workers infected with HIV "who perform invasive procedures not identified as exposure-prone".[217]

(3) "Exposure-prone procedures should be identified by medical/surgical/ dental organizations and institutions at which the procedures are performed."[218]

(4) Health care workers who perform exposure-prone procedures should know their HIV status.

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[215] See, generally, Gostin, "The HIV-Infected Health Care Professional", *supra*, note 212. Elsewhere the author has defined a "significant risk" of transmission as follows: "A risk is significant only if the mode of transmission is scientifically well established, there is a reasonable likelihood that viral transmission will take place, and the potential harm is serious." See Gostin, *supra*, note 59, at 1021.

[216] "Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients during Exposure-Prone Invasive Procedures" (1991), 40 MMWR (No. RR-8).

[217] *Ibid.*, at 5.

[218] *Ibid.*

(5) HIV-infected health care workers should not perform exposure-prone procedures "unless they have sought counsel from an expert review panel and been advised under what circumstances, if any, they may continue to perform these procedures. Such circumstances would include notifying prospective patients of the [health care worker's] seropositivity before they undergo exposure-prone invasive procedures".

(6) Mandatory testing of health care workers for HIV infection is not recommended. "The current assessment of the risk that infected [health care workers] will transmit HIV or HBV to patients during exposure-prone procedures does not support the diversion of resources that would be required to implement mandatory testing programs. Compliance by [health care workers] with recommendations can be increased through education, training, and appropriate confidentiality safeguards."[219]

The CDC guidelines constitutes an attempt to reach a compromise in a very difficult debate. The guidelines expressly reject mandatory testing for all health care workers and state that HIV-infected health care workers who perform invasive procedures not designated as "exposure-prone" need not be restricted in their practice. In rejecting mandatory testing and attempting to define more narrowly the category of procedures that might present a risk of infection to patients, the CDC appears to recognize that in most invasive procedures the risk of transmission is remote, and that even in the case of "exposure-prone" procedures the risk does not justify the costs associated with mandatory testing.

Nonetheless, the guidelines do not identify "exposure-prone" procedures; instead, that difficult and extremely important task is left to medical, surgical, and dental professional organizations. Without guidance the organizations may err on the side of considering most invasive procedures to be exposure-prone, rendering meaningless the attempt to precisely define those procedures at highest risk. Alternatively, some of these organizations may refuse to attempt any definition of exposure-prone procedures because the available data and the CDC recommendations do not persuade them that there is a significant risk of transmission in the performance of invasive procedures.[220] Although the recommendations explicitly reject mandatory testing, they could nonetheless lead to such testing in at least some cases, as well as to demands for legislative action.

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[219] *Ibid.*, at 6.

[220] "Health Units Defy U.S. on AIDS Rules", *The New York Times* (August 30, 1991). The American Medical Association attempted to convene a meeting of forty health care groups to devise a list of "exposure-prone" procedures. Most of the groups declined to assist in the development of this list because they contended that the available data did not indicate that patients were at any significant risk of infection.

A stringent bill passed by the U.S. Senate would have imposed criminal penalties, including a fine of up to $10,000 or not less than ten years in prison, on health care workers who, knowing they are HIV-infected, continue to perform procedures that involve "an invasive physical contact" with the patient.[221] Notably, the proposed legislation extended the definition of these procedures further than the CDC recommendations, to include *any* invasive physical contact, not just exposure-prone procedures. The bill was not passed by the U.S. Congress. Instead Congress passed a substitute bill, which only requires state public health officials to certify that the CDC guidelines or "guidelines which are equivalent have been instituted in the state".[222]

New York was one of the first states to respond to the legislation.[223] The New York State Health Department issued a proposed policy in October, 1991 that reaffirmed its long-standing position that HIV-infected health care workers should not be excluded from the practice of any invasive medical procedure, since the risk of transmission is minimal.[224] Moreover, according to the Department, the diversion of resources into the mandatory testing of health care workers would be wasteful and counterproductive. Instead, the policy reaffirms the importance of infection control measures in the health care setting. A variety of measures are recommended to ensure compliance with infection control measures, including mandatory courses in infection control procedures for all health care workers.[225] The New York proposals differ from the CDC guidelines in that they expressly reject the exclusion of infected health care workers from any invasive procedures.

Along with the New York State Health Department, the CDC recommendations have been criticized by expert observers, including the former Surgeon General of the United States, Dr. C. Everett Koop.[226] It has also been reported that some HIV-infected health care workers refuse to follow CDC guidelines requiring them to restrict their practices or inform their patients of their HIV status.[227] The workers argue that there is no significant risk of infection to their patients. They also argue that disclosing their HIV status would lead to panic among their patients, termination of their practices, loss of their hospital posts, and the commencement of lawsuits against them. This widespread refusal of health care workers to follow the CDC guidelines has led to calls for immediate legislation requiring the mandatory testing of health care workers.

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[221] Amendment 734 to Treasury Bill 2622.

[222] Bill H.R. 2622, 102 Cong., 1st Sess. (1991), passed October 28, 1991 as Pub. L. No. 102-141.

[223] Sack, "Albany Supports Medical Practice Despite AIDS Virus", *The New York Times* (October 9, 1991) A1, A16. This opposition is not uniform, however. A number of other states, notably Illinois, quickly responded to the CDC proposals by passing legislation requiring that all patients be notified if a health care worker is found to be infected.

[224] *Ibid.*; proposed policy (October, 1991).

[225] *Ibid.*

[226] Dr. Koop stated that the risk of being infected by a health care worker "is so remote that it may never be measured", and requiring mandatory testing would be a "worthless" return to the darker days of the AIDS epidemic: "Experts Oppose AIDS Tests for Doctors", *The New York Times* (September 20, 1991) A11.

In response to the debate in the United States, the Canadian Dental Association (CDA), in cooperation with the Federal Centre for AIDS, organized a conference at which the risk of HIV transmission in oral health care delivery was examined. This conference was held after the CDC released their preliminary findings in Dr. Acer's case, but before the publication of the CDC guidelines. After examining all the available evidence from Dr. Acer's case, the CDA reaffirmed its earlier position "that the public is not at risk of infection from HIV or other blood-borne pathogens in the dental office".[228] The CDA concluded that the risk of HIV infection in a dental setting is "infinitesimal", approaching 1 in 1.4 million for the patient who is treated by an HIV-infected dentist.[229]

Rather than endorsing mandatory testing or the exclusion of HIV-infected health care workers from any invasive procedures, the CDA recommended a number of policy initiatives designed to further reduce any risk of infection, including the continued promotion of universal precautions and infection control guidelines and expanded in-office monitoring programs.[230] The CDA also recommended that HIV-infected dentists be

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[227] "Many Doctors Infected with AIDS Don't Follow New U.S. Guidelines", *supra*, note 211.

[228] Canadian Dental Association, "Dentistry Moves to Increase Safety in the Dental Office", press release (April 16, 1991) (hereinafter referred to as "CDA Release").

[229] *Ibid.* Other studies indicate that the risk of acquiring HIV infection during surgery is one in 21 million for every hour of operation, about the same chance that a person will be in a fatal accident on the way to the hospital: (1991), 325 New Eng. J. Med. 888-89, letter to the editor (September 19, 1991).

[230] CDA Release, *supra*, note 228. Policy initiatives emerging from the exercise include:

- continued promotion of the CDA infection control guidelines,
- expanded in-office monitoring programs,
- encouragement of infected or otherwise impaired dental care workers to disclose their condition on a confidential basis to provincial licensing bodies,
- encouragement of licensing authorities and provincial associations to set up mechanisms, where they do not already exist, to support individuals who become incapacitated,

encouraged to disclose their condition, on a confidential basis, to provincial licensing bodies and that these bodies establish mechanisms to support infected dentists who become incapacitated.[231]

The CDC guidelines are similar to the interim guidelines regarding the treatment of HIV-infected physicians issued by the Ontario Medical Association (OMA) in 1988.[232] Those guidelines provide that physicians who suspect they may be HIV-infected should seek appropriate medical care and counselling, including an HIV antibody test. As required under the Ontario HPPA,[233] the results of any finding of HIV infection must be reported to the local medical officer of health. The officer should also be informed that the infected patient is also a physician, "given the professional and public sensitivity of the situation".[234]

Under the OMA guidelines, the physician-patient is permitted to continue to practice, but is required to consult with the medical officer of health so that the officer can monitor the physician and provide infection control guidelines necessary to safeguard patients. The content of these guidelines is presumed to "vary from specialty to specialty, and from practice to practice, but must be consistent with recently published official statements for health professionals or more up-to-date clinical knowledge as available".[235] In the event that the physician cannot comply with the measures required to ensure patient safety, the local medical officer of health may exercise the statutory authority to order that the affected physician conduct himself "in such a manner as not to expose another person to infection".[236]

- development of resource materials to expand the profession's knowledge in this area,
- ensuring that the dental school curriculum continues to provide adequate foundations for practice through its teachings of infection control procedures and ethics,
- continuing partnership with government and other professional groups to provide the public with accurate information on this issue.

[231] *Ibid.*

[232] See Ontario Medical Association, "HIV-Positive Physicians: Interim Guidelines", [1988] Ont. Med. Rev. (August) 10 (hereinafter referred to as "OMA, 'HIV-Positive Physicians'".

[233] *Infra*, ch. 3.

[234] OMA, "HIV-Positive Physicians", *supra*, note 232.

[235] *Ibid.*, at 11.

[236] HPPA, s. 22(4)(*h*).

The OMA and CDA guidelines reject the mandatory testing of health care workers. They contemplate that in most cases the HIV-infected health care worker should be permitted to continue to practise, since there is an insignificant risk of infection to any patient when appropriate precautions are taken. These policies are largely consistent with the policy adopted in October, 1991 by the New York Department of Health in response to the CDC guidelines in which the Department reaffirmed its earlier opposition to the mandatory testing of health care workers and the exclusion of HIV-infected workers from the practice of invasive procedures.[237] The Commission concludes that no exception to a general rule requiring voluntary, specific, and informed consent is justified respecting health care workers. The prevention of transmission in the health care setting is best furthered by strict adherence to universal precautions and the promotion of appropriate infection control procedures.

5. EPIDEMIOLOGICAL SCREENING

In this chapter we have focused on the voluntary, mandatory, and compulsory identification of HIV-infected individuals. It is important to distinguish the process of *identification* from *epidemiological screening*,[238] which attempts to determine the HIV seroprevalence rate in a given population. A study of the ethics of performing anonymous unlinked seroprevalence studies in Ontario was recently completed by the Ministry of Health.[239]

Anonymous unlinked HIV seroprevalance research (sometimes called a "blinded survey") is the most accurate method of obtaining information on seroprevalance rates. Serum or blood samples left over from those routinely collected for other purposes (such as surplus blood samples obtained in a heel-prick from newborns) is first permanently unlinked from any identifying information, and the sample is tested for HIV antibodies.[240] This procedure is designed to provide a random selection of blood samples from which the rate of HIV infection in the given population can be determined.

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[237] However, the OMA and the CDA guidelines were drafted before the July, 1991 publication of the CDC recommendations regarding HIV-infected health care workers. As a result, the OMA and CDA guidelines are now being reconsidered in the light of the most recent CDC recommendations: "Doctors Take Get-Tough Stand on AIDS Virus", *The Globe and Mail*, Toronto (August 15, 1991).

[238] Commentators sometimes distinguish between "testing" and "screening", using the former term to refer to testing individuals and the latter to refer to surveying a group to discover which portion of the group is infected. For the sake of clarity, this report employs "testing" whenever the results are used to identify individuals who are HIV-infected, whether or not the individual is question is a member of a larger group being tested. "Screening" is employed only when the testing is being performed for epidemiological or research purposes and the results are not being used to identify infected individuals.

[239] Ontario, Ministry of Health, *HIV Seroprevalence Studies Report* (February, 1991) (hereinafter referred to as "*HIV Seroprevalence Studies Report*").

Because epidemiological screening, if properly conducted, is performed in such a way as to ensure that the test results remain anonymous and unlinked (that is, the data obtained can never be used to identify or "link" the results of any HIV test with any specific individual), epidemiological studies do not raise the difficult issues associated with the identification of HIV-infected persons and the confidentiality of HIV-related information. Because identifiable individuals are not being tested for HIV infection, voluntary, specific, and informed consent is not relevant. For this reason, where epidemiological research is properly conducted, consent is generally considered unnecessary.[241]

Data on the prevalence, incidence, and distribution of HIV infection in a population can be used to monitor the spread of the infection, to increase knowledge of the mechanisms of transmission, to assist in the design of public health measures to prevent the spread of the disease, to evaluate the effectiveness of current interventions, and to plan for the provision of services.[242] Collecting information for such purposes is almost universally regarded as essential to improving society's ability to cope with this epidemic.[243]

The Federal Centre for AIDS has published a set of guidelines on the ethical and legal considerations in anonymous unlinked HIV seroprevalence research;[244] the guidelines, which are widely regarded as an exemplary model,[245] affirm that anonymous unlinked HIV seroprevalence research is the most accurate method of estimating the extent of HIV infection in a population. Studies consistently show that the persons most likely to be infected are also the persons least likely to consent to participate in HIV epidemiological research;[246] therefore, if consent is necessary to perform those studies, the accuracy and utility of the data obtained will be significantly reduced. To ensure that the epidemiological data is as accurate as possible, testing must be performed on a representative sample; this objective is frustrated if informed consent is a prerequisite to testing. However, because epidemiological research can be conducted in such a way that the results can never be used to identify infected individuals, consent is no longer relevant.

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[240] See, for example, *HIV Seroprevalence Studies Report*, *ibid.*, Appendix 1, which describes an HIV seroprevalence study in women of childbearing age conducted in Ontario.

[241] Voluntary HIV testing with the patient's specific, informed consent should, of course, always be available to any individual who wishes to determine his or her HIV status.

[242] *Confronting AIDS: Update 1988*, *supra*, note 18, at 117.

[243] See, for example, *HIV and AIDS: Canada's Blueprint*, *supra*, note 17, at 44.

[244] Canada, Federal Centre for AIDS, "Guidelines on Ethical and Legal Considerations in Anonymous Unlinked HIV Seroprevalence Research" (1990), 143 Can. Med. A.J. 625 (hereinafter referred to as "Federal Centre for AIDS, 'Guidelines'").

[245] See, for example, Hankins *et al.*, "HIV Infection among Quebec Women Giving Birth to Live Infants" (1990), 143 Can. Med. A.J. 885, at 890.

A number of American states, particularly those that have already enacted legislation requiring informed consent for HIV testing, have included statutory provisions that explicitly exempt testing and the collection of HIV-related information for research and epidemiological purposes, provided that the tests are conducted in a way that precludes the linking of the diagnosis to the person tested.[247]

Consistent with most of the foregoing analysis, the Ontario Ministry of Health's recent report on HIV seroprevalence studies also concludes that informed consent need not be obtained from the subjects of anonymous unlinked seroprevalence studies;[248] however, the subjects should, at a minimum, be provided with "specific information" about the seroprevalence study, and if a subject chooses to "opt out" of the study that choice should be respected.[249] This recommendation flows from the Ministry's finding that although a requirement of informed consent may jeopardize the accuracy of the epidemiological research, individuals still have the right "to know what will happen to their bodily fluids and parts when removed if something other than what one would reasonably assume would normally be done is planned".[250]

It is not clear how this requirement of "specific information" differs from a requirement of informed consent, although the report seems to suggest that the information supplied could be somewhat less detailed than that which might be necessary to obtain informed consent. Finally, in apparent recognition that a requirement of "specific information" may jeopardize some epidemiological research, the report also states that an exception to this requirement may be acceptable if non-professionals and representatives of the target population are sufficiently consulted.[251]

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[246] *Ibid.*, at 891.

[247] Edgar and Sandomire, "Medical Privacy Issues in the Age of AIDS: Legislative Options" (1990), 16 Am. J. L. & Med. 155, at 171-172. See, for example, New York Act, §2781.6(b).

See, also, *HIV Screening of Pregnant Women and Newborns*, *supra*, note 141, which examines the issue of whether pregnant women should be tested for HIV infection. The Committee concludes that testing should only be performed with the voluntary, specific, and informed consent of the pregnant women (at 1). The Committee also endorsed the continuation of anonymous newborn HIV screening for surveillance purposes (at 2).

[248] *HIV Seroprevalence Studies Report*, *supra*, note 239, at 53.

[249] *Ibid.*

[250] *Ibid.*, at 53.

The issue of the extent to which persons have the right to control their bodily fluids and parts raises a number of very complex issues well beyond the scope of this report. Nonetheless, as in the case of anonymous unlinked seroprevalence studies, where a blood sample has already been extracted for other purposes, will be discarded if not used for the study, and cannot be linked to any individual, it is not clear that the subject has a significant claim to retain all rights to control this blood sample. Moreover, this claim appears even less significant once it is weighed against the very substantial interest the public has in accurately assessing seroprevalence rates. As a result, it is not at all clear that a compelling argument can be made that subjects should be provided with "specific information" about a seroprevalence study or provided with any opportunity to "opt out" of the study. This argument is made even less compelling by the well established fact that this procedure will compromise the quality and accuracy of the data obtained, because the persons most likely to be infected are the ones most likely to "opt out".

Epidemiological or research studies cannot harm any individual (all identifying information is removed when the testing is conducted); however, they may show that a certain population or group has an unusually high incidence of HIV infection. Members of a group potentially could suffer discrimination as a result.[252] This raises the difficult question about the nature of demographic information collected about the tested group.[253] The Federal Centre for AIDS guidelines recommend that researchers should anticipate the potential for indirect harm to groups or individuals that might result from epidemiological research.[254] It may even be inappropriate to collect certain demographical data if this information might be used to discriminate against certain groups. On balance, however, data collected from properly conducted epidemiological studies are extremely important for the purposes of targeting prevention efforts and planning for future health care services in Ontario, and justify any indirect harm to populations or demographic areas.[255] The Commission recommends that, subject to the recommendation in section 3(a) (Donors of Blood Products or Bodily Tissues) of this chapter, the HIV-specific statute should provide that no HIV-related test should be performed without first receiving the voluntary, specific, and informed consent of the patient, except where an HIV-related test is performed as part of an anonymous (unlinked) HIV screening program for epidemiological or research purposes.

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[251] *Ibid.*

[252] Edgar and Sandomire, *supra*, note 247, at 172.

[253] A recent seroprevalence study in Quebec, for example, identified neighbourhoods in Montreal with the highest seroprevalence rates: Hankins, *supra*, note 245, at 889.

[254] Federal Centre for AIDS, "Guidelines" *supra*, note 244, at 627.

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[255] *HIV and AIDS: Canada's Blueprint*, *supra*, note 17, at 44, which states: "To identify the dimensions and characteristics of HIV infection and AIDS in Canada, we must: ... undertake *seroprevalence and seroepidemiologic research*. Accurate estimates of HIV infection rates are required to determine Canada's future needs in health and social services, to develop prevention strategies and to evaluate their effectiveness among subgroups in the population".

CHAPTER 3

CONFIDENTIALITY OF HIV-RELATED PERSONAL INFORMATION: COMPULSORY NOMINAL REPORTING

1. INTRODUCTION

This chapter constitutes an overview of one aspect of the public health debate involving the confidentiality and disclosure of HIV-related personal information: Ontario's policies of compulsory nominal reporting and state-supervised contact tracing.[1] We will consider the legal and practical aspects of these measures in the context of two important social interests—the principle of confidentiality and the protection of public health.

The appropriate collection, use, and disclosure of HIV-related personal information can benefit society.[2] But the unauthorized disclosure of an individual's serological status may lead to social opprobrium, estrangement of family and friends, and to loss of employment, housing, and insurance.[3]

The majority of people infected with HIV in Canada are members of groups that have been subject to discrimination.[4] This is particularly important because at the moment the chief weapon for combatting the spread of this disease relies upon influencing behaviour. As a result, public health officials, professional medical associations, and AIDS support groups, among others, have called for a strengthening of confidentiality protections for HIV-related personal information.[5] Where is the line, however, between the need for patient confidentiality and the protection of public health?[6] Should there be a requirement to maintain patient confidentiality if an unsuspecting partner is at significant risk of infection?[7] Should the line be extended to include the groups in society that assert a "right to know" the serological status of HIV-infected individuals?[8]

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[1] "HIV-related personal information" is defined broadly in this chapter to mean any information that "links" a person with AIDS or HIV infection, whether or not that person actually has AIDS or HIV infection: Ontario, Information and Privacy Commissioner/ Ontario, *HIV/AIDS: A Need for Privacy* (October, 1990), at 9-10 (hereinafter referred to as the "Ontario Privacy Commissioner's Report").

[2] Proper disclosure of HIV-related information may enable health care and education programs to be implemented where they are most needed, treatment to be provided to those who are infected, and partners who are at risk of infection to be notified.

[3] Gostin, "A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy" (1990), 5 Notre Dame J. L., Ethics & Pub. Pol'y 7, at 27.

[4] *Ibid.*

In Ontario, doctors are bound both legally and ethically to maintain patient confidentiality.[9] Except in compliance with reporting requirements, physicians cannot reveal HIV-related personal information to anyone, and warning a partner at significant risk of HIV infection without the patient's consent might constitute professional misconduct.[10]

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[5] The Canadian Medical Association (CMA), for instance, stresses the need to respect the confidentiality of patients with HIV infection and consequently recommends that legal and regulatory safeguards be put in place to protect such confidentiality: "A CMA Position: Acquired Immunodeficiency Syndrome" (1989), 140 Can. Med. A.J. 64A, at 64B. Other groups or organizations advocating the strengthening of confidentiality provisions for HIV-related information include: Casey House Hospice, *HIV Antibody Testing*, submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (February 7, 1991), at 2; Halton AIDS Advisory Committee, submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (April 10, 1991), at 2; City of Toronto Department of Public Health, *Reporting of HIV Antibody Status to Public Health Authorities* (March, 1989), submission to Ontario Law Reform Commission for Report on Testing for HIV Infection (January 11, 1991), at 16; AIDS Action Now!, *HIV Testing and the Needs of People Living with AIDS and HIV*, submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (March 4, 1991), at 14; Canadian Red Cross Society, submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (April 19, 1991), at 4; Board of Directors of the Toronto and Central Ontario Region of Hemophilia Ontario, submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (March 7, 1991), at 1; Association of Local Official Health Agencies, *Briefing Notes on the Ontario Law Reform Commission's Project on HIV Testing* (January 31, 1991), submission to the Ontario Law Reform Commission for Report on Testing for HIV Infection (February 6, 1991), at 6.

[6] Gostin, *supra*, note 3, at 28.

[7] *Ibid.* Gostin, "The Politics of AIDS: Compulsory State Powers, Public Health, and Civil Liberties" (1989), 49 Ohio St. L.J. 1017, at 1021, notes that the concept of "significant risk" has never been well clarified or defined. It should be based upon epidemiologic evidence of the gravity of the harm and the probability of the harm occurring. "A risk is significant only if the mode of transmission is scientifically well established, there is a reasonable likelihood that viral transmission will take place, and the potential harm is serious": *ibid.*, at 1021.

[8] Gostin, *supra*, note 3, at 28. These groups include health care workers, patients, police, firefighters, and many others.

[9] For example, the Canadian Medical Association, *Code of Ethics* (April, 1990) Principle IV (hereinafter referred to as "CMA *Code of Ethics*") states: "Protect the patient's secrets"; the Hippocratic Oath includes the vow: "Whatever, in connection with my professional practice or not, in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret": *The New Encyclopaedia Britannica* (15th ed., 1989), Vol. 23, at 889; CMA *Code of Ethics*, *supra*, Rule 6 states: "An ethical physician...will keep in confidence information derived from a patient or from a colleague regarding a patient, and divulge it only with the permission of the patient except when otherwise required by law". In addition, see Ontario's *Health Protection and Promotion Act*, R.S.O. 1990, c. H.7, s. 39 (hereinafter referred to as "HPPA"); see, also, s. 27(22) of R.R.O. 1980, Reg. 448, under the *Health Disciplines Act*, R.S.O. 1990, c. H.4: *infra*, this ch., sec. 2.

Ontario's policies of compulsory nominal reporting and contact tracing are at the heart of the problem. While debates continue about appropriate testing policies, studies show that people who are at a high risk of HIV infection are especially reluctant to seek testing if name-specific reporting is required.[11] Compelling physicians to include personally identifying information on reports to public health authorities does not significantly contribute to research, counselling, or treatment, while it increases the chances that patients' privacy rights will be infringed.[12]

Many U.S. states now have HIV-specific legislation that protects the confidentiality of HIV-related personal information.[13] Such statutes may achieve two important goals: privacy protection for HIV-infected persons, and guidance for health care professionals who must try to balance the privacy rights of their patients with the protection of public health.[14]

The line should be drawn to allow the disclosure of HIV-related personal information only in cases where a significant risk of HIV infection presents a danger to identifiable, unsuspecting individuals. We believe that strong confidentiality protection of information pertaining to HIV-related testing and treatment promotes the social interest in individual privacy as well as the public health. Exceptions to the principle of confidentiality should be clearly justified.

In the next section of this chapter we will examine the current requirements concerning compulsory physicians' reporting of HIV infection and state-supervised contact tracing in Ontario. We will consider the impact on public health and the privacy implications of those policies, alternatives to compulsory reporting, and a state-supervised program of contact tracing, using examples of physician non-compliance with required practice. We will also analyze the Ministry of Health's proposals for reform, and describe a comprehensive approach to confidentiality and disclosure of HIV-related personal information.

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[10] *Ibid.*; HPPA, ss. 25, 26.

[11] Kegeles *et al.*, "Many people who seek anonymous HIV-antibody testing would avoid it under other circumstances" (1990), 4 AIDS 585, at 585. The Ontario Ministry of Health has responded to this problem by implementing anonymous testing: see *infra*, this ch., sec. 4(b); O.Reg. 490/85, as am. by O.Reg. 749/91.

[12] Hodgson, "The Legal and Public Policy Implications of Human Immunodeficiency Virus Antibody Testing in New Zealand" (1989), at 65, in *Legal Implications of AIDS*, papers presented at a seminar held by the Legal Research Foundation, University of Auckland (May, 1989), at 65.

[13] Dickens, "Confidentiality and the Duty to Warn", in Gostin (ed.), *AIDS and the Health Care System* (1990) 98, at 100.

[14] *Ibid.*

2. PHYSICIAN REPORTING OF HIV INFECTION UNDER THE *HEALTH PROTECTION AND PROMOTION ACT*

(a) Introduction

The *Health Prevention and Promotion Act* (HPPA) establishes a comprehensive legislative scheme for public health concerns in Ontario. The HPPA and its regulations define the reporting responsibilities of physicians and the authority of the medical officer of health to monitor and control the spread of disease.

The purpose of the Act is to provide for the organization and delivery of public health programs and services, the prevention of the spread of disease, and the promotion and protection of the health of the people of Ontario.[15] The HPPA and its regulations establish a classification scheme for specified infectious diseases.

(b) Disease Classification

The HPPA establishes three categories of disease: reportable, communicable, and virulent. The words "communicable" and "virulent" are not used in their medical or epidemiological sense in the Act; they are terms that serve to distinguish diseases with differing public health significance. The reportable and communicable diseases are specified in the regulations. The communicable diseases are a subset of the reportable diseases; and the twelve virulent diseases, which are listed in section 1(1) of the HPPA (cholera, diphtheria, ebola virus disease, gonorrhea, hemorrhagic fever, Lassa fever, leprosy, Marburg virus disease, plague, syphilis, smallpox, and tuberculosis) are a subset of the communicable diseases. Local medical officers of health are granted broad powers under the HPPA to monitor and control the spread of communicable and virulent diseases. Ontario Regulations 161/84[16] and 162/84[17] designate AIDS as a communicable disease and a reportable disease respectively. Neither AIDS nor HIV infection is designated as a virulent disease.

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[15] HPPA, s. 2.

[16] As am. by O.Reg. 698/86 and O.Reg. 666/88.

[17] As am. by O.Reg. 699/86 and O.Reg. 667/88.

(c) The Duty to Report

The duty of reporting cases of specified diseases to public health authorities is found in Part IV of the HPPA.[18] The duty extends to, among others, school principals,[19] hospital administrators, and superintendents of certain specified institutions, such as nursing homes.[20] In addition, operators of laboratories[21] and physicians[22] must report cases of certain specified diseases to the medical officer of health.

Section 25 of the HPPA obliges a physician to report a patient who "has or may have a reportable disease". Section 26 requires a physician to report a person who "is or may be infected with an *agent* of a communicable disease".[23] It is generally accepted that HIV is the agent of AIDS;[24] therefore physicians in Ontario must report all cases of AIDS and HIV infection to public health authorities pursuant to the provisions of sections 25 and 26 of the HPPA:[25]

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[18] HPPA, ss. 25-31.

[19] HPPA, s. 28.

[20] HPPA, s. 27.

[21] HPPA, s. 29. Operators of laboratories are required to report each case of a "positive laboratory finding in respect of a reportable disease": *ibid.* All findings of AIDS and HIV infection are reported to the medical officer of health; an exemption from reporting is permitted if the test "is in relation to professional services provided" at one of the designated clinics now offering anonymous testing services in Ontario: O. Reg. 490/85, *supra*, note 11, s. 5a, as am. by O.Reg. 749/91. *Infra*, this ch., sec. 4(b).

[22] HPPA, ss. 25, 26.

[23] The Ministry of Health has modified the reporting rules pursuant to s. 26 of the HPPA for physicians who provide professional services at any of the specified clinics in Ontario that now offer anonymous testing: O.Reg. 490/85, *supra*, note 11, s. 5a, as am. by O.Reg. 749/91. *Infra*, this ch., sec. 4(b).

[24] Canada, Health and Welfare, *HIV and AIDS: Canada's Blueprint* (1990), at 8.

[25] All other provinces and territories require reporting of AIDS cases to public health authorities. See Alberta *Public Health Act*, S.A. 1984, c. P-27.1, ss. 31, as am. by 1988, c. 41, s. 9, 33, 34, and Communicable Diseases Regulation, Alta. Reg. 238/85; British Columbia Health Act Communicable Disease Regulation, B.C. Reg. 4/83, ss. 2, 3, 4, and Schedule A, as am. by B.C. Reg. 31/85; Manitoba *The Public Health Act*, R.S.M. 1987, c. P210, and Diseases and Dead Bodies Regulation, Man. Reg. 338/88R, s. 43; New Brunswick General Regulation—Health Act, N.B. Reg. 88-200, s. 94; Newfoundland *The Communicable Diseases Act*, R.S.N. 1970, c. 52, ss. 3-5 and Schedule, as am. by 1974, c. 25, s. 2; Nova Scotia Regulations in Respect of the Communicable Diseases, N.S. Reg. 28/57, ss. 2, 11(15A), as en. by N.S. Reg. 171/85, ss. 2, 11(15A); Prince Edward Island Notifiable and Communicable Diseases Regulations, P.E.I. Reg. EC 330/85, ss. 6, 7, 17, as am. by

25. A physician or a person registered under Part II, IV, V or VI of the *Health Disciplines Act* to practise a health discipline or a person registered as a drugless practitioner under the *Drugless Practitioners Act* who, while providing professional services to a person who is not a patient in or an out-patient of a hospital, forms the opinion that the person has or may have a reportable disease shall, as soon as possible after forming the opinion, report thereon to the medical officer of health of the health unit in which the professional services are provided.

26. A physician who, while providing professional services to a person, forms the opinion that the person is or may be infected with an agent of a communi-

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P.E.I. Reg. EC 409/87; Quebec *Public Health Protection Act*, R.S.Q., c. P-35, s. 5, as am. by 1981, c. 22, s. 105, and Regulation respecting the application of the Public Health Act, R.R.Q. 1981, c. P-35, s. 30, as am. by O.C. 975-83, s.3; O.C. 1497-86, s. 2; and Schedule 13, as am. by O.C. 1497-86, s. 4; Saskatchewan Regulations Governing Control and Notification of Communicable Disease, Sask. Reg. 307/69, ss. 1(1)(*o*), 2, 3; Northwest Territories *Public Health Act*, R.S.N.W.T. 1974, c. P-10, Schedule A, and Communicable Diseases Regulations, R.R.N.W.T. 1980, Reg. 212, ss. 4, 5; Yukon *Public Health Act*, R.S.Y.T. 1986, c. 136, s. 2; Regulation for the Control of Communicable Diseases in the Yukon Territory, Y.T.O.I.C. 1961/48, ss. 3, 4, 10. See, generally, McGill Centre for Medicine, Ethics and Law (AIDS Research Program) *Responding to HIV/AIDS in Canada*, by Hamblin *et al.* (1990) (hereinafter referred to as "*Responding to HIV/AIDS in Canada*"); Flanagan, "Equality Rights for People with AIDS: Mandatory Reporting of HIV Infection and Contact Tracing" (1989), 34 McGill L.J. 530, at 550; Casswell, "Disclosure by a Physician of AIDS-Related Patient Information: An Ethical and Legal Dilemma" (1989), 68 Can. B. Rev. 225, at 232.

HIV seropositivity is reportable in all provinces and territories except Quebec, Alberta, British Columbia, and the Yukon. See Alberta *Public Health Act*, *supra*, ss. 31, as am. by 1988, c. 41, s. 9, 33, 34; Communicable Diseases Regulation, *supra*; British Columbia Health Act Communicable Disease Regulation, *supra*, ss. 2, 3, 4, and Schedule A as am. by B.C. Reg. 31/85; Manitoba Diseases and Dead Bodies Regulation, *supra*, ss. 8(3), 47(e); New Brunswick General Regulation—Health Act, *supra*, s. 94; Newfoundland *The Communicable Diseases Act*, *supra*; ss. 3-5 and Schedule, as am. by 1974, c. 25, s. 2; Nova Scotia Regulations in Respect of the Communicable Diseases, *supra*, ss. 2, 11(15A), as en. by N.S. Reg. 171/85; Ontario HPPA, ss. 25-29, and O.Regs. 161/84, 162/84, 490/85, as am. by O.Reg. 749/91; Prince Edward Island Notifiable and Communicable Diseases Regulations, *supra*, ss. 6, 7, as am. by P.E.I. Reg. EC 409/87; Quebec *Public Health Protection Act*, *supra*, s. 5 as am. by S.Q. 1981, c. 22, s. 105, and Regulation respecting the application of the Public Health Act, R.R.Q. 1980, c. P-35, s. 30, as am. by O.C. 975-83, s. 3; O.C. 1497-86, s. 2; and Schedule 13; as am. by O.C. 1497-86, s. 4; Saskatchewan Regulations Governing Control and Notification of Communicable Disease, *supra*, ss. 1(1)(*o*), 2, 3; Northwest Territories *Public Health Act*, *supra*, Schedule A, and Communicable Diseases Regulations, *supra*, ss. 4, 5; Yukon *Public Health Act*, *supra*, s. 2. Regulation for the Control of Communicable Diseases in the Yukon Territory, *supra*, ss. 3, 4, 10.

However, as a matter of practice, findings of HIV seropositivity are reported in Alberta, British Columbia, and the Yukon: see *Responding to HIV/AIDS in Canada*, *supra*, at 3-3; 4-7; 14-3. Quebec does not require the reporting of positive HIV antibody test results: *ibid.*, at 11-4. Ontario, however, has modified its rules concerning nominal testing and reporting of HIV seropositivity. See, *infra*, this ch., sec. 4(b).

cable disease shall, as soon as possible after forming the opinion, report thereon to the medical officer of health of the health unit in which the professional services are provided.

The clear wording of sections 25 and 26 requires physicians to report all suspected cases of AIDS and HIV seropositivity, as well as those that have been clinically diagnosed.[26]

(d) The Information Reported

Section 1(1) and (2) of Ontario Regulation 490/85 require a physician who is reporting a case of AIDS or HIV infection pursuant to section 25 or 26 of the HPPA to identify the individual who is the subject of the report by name, address, date of birth, sex, and date of onset of symptoms, and such additional information as the medical officer of health considers necessary.[27]

When the patient's illness is diagnosed as AIDS, further information must be reported by the physician as specified in section 5 para. 3 of Ontario Regulation 490/85,[28] including the patient's "risk classification"; such information includes the possible means of acquisition of the disease (for example, whether the patient is homosexual or bisexual, is an intravenous drug user, has haemophilia, or is the heterosexual partner of any of those persons).

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[26] As of January 1, 1992, an amendment to O.Reg. 490/85 by O.Reg. 749/91 permits an exemption from the reporting requirements pursuant to s. 26 of the HPPA for patients who have received counselling about the prevention of HIV transmission prior to the test, and whose tests are performed in one of the clinics specified in the regulation.

[27] 1.—(1) A report required under section 25, 26 or 27 of the Act shall, with respect to the person to whom the report relates, contain the following information:

1. Name and address in full.
2. Date of birth in full.
3. Sex.
4. Date of onset of symptoms.

(2) A person who makes a report under section 25 or 26 of the Act and gives the information set out in subsection (1) shall, upon the request of the medical officer of health, give to the medical officer of health such additional information respecting the reportable disease or communicable disease, as the case may be, as the medical officer of health considers necessary.

See, also, O.Reg. 490/85, as am. by O.Reg. 749/91. The Ministry of Health has modified the reporting rules pursuant to s. 26 of the HPPA for physicians who provide professional services at any of the specified clinics in Ontario that offer anonymous testing.

[28] 3. Acquired Immune Deficiency Syndrome (AIDS):

i. The date of diagnosis.

ii. the name and address of the physician attending the person.

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iii. The name of the hospital and the date of admission if the person is admitted to a hospital.

iv. Medical conditions including laboratory findings and date of diagnosis that may be indicative of cellular immune deficiency and Acquired Immune Deficiency Syndrome.

v. Other medical conditions that may have caused immunosuppression.

vi. Date and place of donation of blood or blood products.

vii. Current status of person infected (alive or dead). If dead, date and place of death.

viii. The risk classification.

A. Evidence of a possible means of disease acquisition, that is, is the person,

1. a homosexual or bisexual,

2. an intravenous drug abuser, or

3. a hemophiliac.

B. Exposure factors under investigation, that is, is or was the person,

1. born in Haiti or of Haitian parentage,

2. a heterosexual partner of a person who may have Acquired Immune Deficiency Syndrome or who is,

i. a homosexual or bisexual,

ii. an intravenous drug abuser, or

iii. a hemophiliac, or

3. exposed to a blood transfusion or blood product and if so where and when.

C. Children, that is, is the person,

1. a child under one year of age, or

2. a child one year or more of age but less than sixteen years of age.

D. Other cases of Acquired Immune Deficiency Syndrome that cannot be classified under sub-subparagraph A, B or C.

Reports identifying the affected individual are also required of laboratories in each case of a positive finding of a reportable disease,[29] and of physicians signing death certificates where they become aware of a reportable disease.[30] Failure to make a report in the case of a communicable or reportable disease as required by the HPPA and its regulations is an offence under the Act.

(e) ENFORCEMENT

Section 100(2) of the HPPA states that any person who contravenes a requirement under Part IV to make a report in respect of a reportable or a communicable disease is guilty of an offence. Any person who contravenes a regulation is also guilty of an offence.[31] The penalty upon conviction is a fine of not more than $5,000 for every day on which the offence continues.[32] Any physician who fails to comply with the reporting requirements of sections 25 and 26 is guilty of an offence.[33] Non-compliance with the confidentiality provisions of the HPPA is an offence punishable by fine.[34]

(f) CONFIDENTIALITY

In view of the sensitive nature of HIV-related personal information and the potential for discrimination should unauthorized disclosure occur, it is vital that the confidentiality of such information be assured. The HPPA attempts to safeguard the confidentiality of personally identifying information pertaining to cases of certain specified diseases. In particular, section 39 prohibits the disclosure of identifying information received in reports relating to communicable, reportable, or virulent diseases.[35] The section states that

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[29] HPPA, s. 29; see, also, O.Reg. 490/85, as am. by O.Reg. 749/91, which exempts laboratories from reporting, under s. 29 of the HPPA, the name and address of a person testing positive "for an agent of AIDS" if the test has been performed at one of the designated clinics that provide anonymous testing services in Ontario.

[30] HPPA, s. 30.

[31] HPPA, s. 100(4).

[32] HPPA, s. 101.

[33] Despite the considerable penalties for non-compliance under the Act, some physicians have refused to comply with the HPPA's strict reporting provisions: *infra*, this ch., sec. 4(a).

[34] HPPA, ss. 100(3), 101.

[35] Section 39 of the HPPA provides as follows:

> 39.—(1) No person shall disclose to any other person the name of or any other information that will or is likely to identify a person in respect of whom an application,

"[n]o person shall disclose to any other person the name of or any other information that will or is likely to identify" a person who is the subject of an application, order, certificate or report.

There are exceptions to this general rule.[36] An exception is made where the person consents to the disclosure,[37] where the disclosure is made for the purposes of public health administration,[38] or where the disclosure is made in connection with proceedings under the HPPA, the *Health Disciplines Act*,[39] the *Public Hospitals Act*,[40] the *Health Insurance Act*,[41] the *Canada Health Act*[42] or the *Criminal Code* (Canada),[43] or any regulations thereunder.[44] Any person who contravenes section 39 is guilty of an offence punishable upon conviction by a maximum fine of $5,000 for every day the offence continues.[45]

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order, certificate or report is made in respect of a communicable disease, a reportable disease, a virulent disease or a reportable event following the administration of an immunizing agent.

(2) Subsection (1) does not apply,

(*a*) in respect of an application by a medical officer of health to the Ontario Court (Provincial Division) that is heard in public at the request of the person who is the subject of the application;

(*b*) where the disclosure is made with the consent of the person in respect of whom the application, order, certificate or report is made;

(*c*) where the disclosure is made for the purposes of public health administration;

(*d*) in connection with the administration of or a proceeding under this Act, the *Health Disciplines Act*, the *Public Hospitals Act*, the *Health Insurance Act*, the *Canada Health Act* or the *Criminal Code* (Canada), or regulations made thereunder; or

(*e*) to prevent the reporting of information under section 72 of the *Child and Family Services Act* in respect of the abuse or the suspected abuse of a child.

[36] HPPA, s. 39(2)(*a*)-(*e*).

[37] HPPA, s. 39(2)(*b*).

[38] HPPA, s. 39(2)(*c*).

[39] *Supra*, note 9.

[40] R.S.O. 1990, c. P.40.

[41] R.S.O. 1990, c. H.6.

[42] R.S.C. 1970, c. M-8, rep. by 1983-84, c. 6, s. 32.

[43] R.S.C. 1985, c. C-46.

[44] HPPA, s. 39(2)(*d*).

[45] HPPA, ss. 100(3), 101.

Ontario physicians are also bound by section 27(22) of Regulation 448,[46] which defines professional misconduct to include "giving information concerning a patient's condition or any professional services performed for a patient to any person other than the patient without the consent of the patient unless required to do so by law." These statutory duties of medical confidentiality are enhanced by the physician's professional duties of confidentiality[47] and by the physician-patient relationship itself, which is fiduciary.[48]

(g) COMPULSORY NOMINAL REPORTING

The requirement that physicians report to the medical officer of health the names or other personally identifying information of patients who test positive for HIV infection as part of the testing procedure is termed "nominal testing and reporting" or simply "nominal reporting". The process begins when a doctor, with the patient's consent, orders an HIV antibody test on a Ministry of Health test requisition form. The physician's name is always included on the test requisition; when the patient is tested nominally, his or her name must also appear on the form. It may take two weeks for the physician to receive the test result. If the result is positive, the central laboratory reports directly to the medical officer of health,[49] who receives a copy of the requisition and the result. The provincial government then reports to the Federal Centre for AIDS (FCA) all cases of AIDS, but not cases of HIV infection that have not progressed to AIDS. The patient's name does not appear on the report to the FCA.

The medical officer of health then asks the physician to complete an "HIV Follow-Up Form", which contains the patient's initials, possible sources of infection, and the names of the patient's partners.[50] The medical officer of health communicates with the physician at this point to determine whether public health officials should proceed with the provincial program of tracing the infected person's contacts.

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[46] *Supra*, note 9.

[47] See, for example, the CMA *Code of Ethics*, *supra*, note 9, Principle IV, which states: "Protect the patient's secrets", and Rule 6 of the CMA *Code of Ethics*, which states: "An ethical physician...will keep in confidence information derived from a patient or from a colleague regarding a patient, and divulge it only with the permission of the patient except when otherwise required by law."

The Hippocratic Oath includes the vow: "Whatever, in connection with my professional practice or not, in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret": *The New Encyclopaedia Britannica*, *supra*, note 9, at 889.

[48] North and Rothenberg, "The Duty to Warn 'Dilemma': A Framework for Resolution" (1989), 4 AIDS & Pub. Pol'y J. 133. The duty of confidentiality has also been recognized at common law. See, for example, *A.B. v. C.D.* (1851), 14 Sess. Cas. (2d) 177 (Scot. Ct. Sess.); Steel and Rodgers-Magnet (eds.), *Issues In Tort Law* (1983), at 293.

[49] HPPA, s. 29; see, also, O.Reg. 490/85, as am. by O.Reg. 749/91.

(h) CONTACT TRACING

"Contact tracing" or "partner notification" is the identification of sexual or needle-sharing partners of HIV-infected patients so they may be counselled and offered testing. The objective is to inhibit partners from engaging in risky behaviour, either with the patient or with others. One author has characterized the two main types of contact tracing as voluntary notification (notification of partners by the patient or personal physician with the patient's consent) and statutory notification (notification by public health authorities, usually by virtue of some statutory regime).[51]

Ontario provides for a comprehensive, state-driven partner notification process of a patient's previous sexual or needle-sharing contacts.[52] The HPPA permits disclosure of identifying information for the purposes of public health administration.[53] This exception enables the medical officer of health to proceed with partner notification, and it may operate to protect public health officials from liability with respect to the disclosure.[54]

If the physician notifies contacts without the patient's consent, he may be guilty of professional misconduct.[55] Such notification may also constitute a breach of medical confidentiality, for which a number of potential causes of action exist.[56] Unless the patient herself has made contact with her partners or has consented to the physician's performing contact tracing, the public health official will do so.

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[50] O.Reg. 490/85, *ibid.*, s. 1(2), requires physicians who have made a report pursuant to the HPPA to provide the medical officer of health with "such additional information respecting the reportable disease or communicable disease...as the medical officer of health considers necessary".

[51] Hodgson, *supra*, note 12, at 65.

[52] Gemmill, "The Role of Public Health in the HIV Epidemic" (1989), 80 C.J. Pub. Health (Supp. 1) S15, at S16; Ontario Privacy Commissioner's Report, *supra*, note 1, at 22. In one recent study in which full responsibility for notifying partners was given to the patient or to public health officials, notification by public health officials was significantly more effective. Results indicated that 50 percent of the partners in the public health group were notified, whereas only 7 percent of the partners were notified in the patient group. See Landis *et al.*, "Results of a Randomized Trial of Partner Notification in Cases of HIV Infection in North Carolina" (1992), 326 New Eng. J. Med. 101.

[53] HPPA, s. 39(2)(*c*).

[54] *Responding to HIV/AIDS in Canada*, *supra*, note 25, at 9-8.

[55] Reg. 448, *supra*, note 9, s. 27(22); see, also, HPPA, s. 39.

For the purposes of contact tracing, the medical officer of health requires the name of the infected person (or "index", in the public health lexicon), and the names of the index's contacts.[57] If the physician knows the names of the patient's partners, he must disclose them to the medical officer of health even without the patient's consent.[58] Once the identity of the index and contacts is established, the medical officer of health proceeds with contact tracing.

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[56] See, generally, Dickens, *supra*, note 13, Sharpe, *The Law and Medicine in Canada* (2d ed., 1987), at 182-83; Sneiderman, Irvine, and Osborne, *Canadian Medical Law: An Introduction for Physicians and Other Health Care Professionals* (1989), at 169-87; Casswell, *supra*, note 25, at 229. Theoretically, legal avenues by which aggrieved patients may bring suit for unwarranted disclosure of medical confidentiality include the equitable action for breach of confidentiality; actions in contract, defamation, or the tort of negligence; and breach of a statutory duty. Each has its limitations, however. In an equitable action, it is doubtful whether a plaintiff has any hope of recovering damages pursuing an action for breach of confidence: see, for example, Sneiderman, Irvine, and Osborne, *supra*, at 171.

Arguably, an obligation to maintain confidentiality is both an element of mutually agreed services between doctor and patient, and an aspect of a standard of care in accordance with the performance of professional duty: Dickens, *supra*, note 13, at 102. Breach of confidentiality thus could give rise to a suit for breach of contract, although such actions are extremely rare: see *A.B. v. C.D.*, *supra*, note 48. Alternatively, unwarranted disclosure could give rise to an action in negligence: see *Furniss v. Fitchett*, [1958] N.Z.L.R. 396. The likelihood of this tort's success will depend upon the existence of a legal duty of care owed to the patient and, of course, proof of damage. Mere "emotional" suffering does not amount to actionable injury in such cases. If the medical disclosure was untruthful, an action in defamation may lie against the physician: *Halls v. Mitchell*, [1928] S.C.R. 125, [1928] 2 D.L.R. 97. However, defences such as absolute and qualified privilege and the stringent requirements for the successful application of this tort make it a less than satisfactory vehicle for breach of medical confidentiality.

While a statute-based claim might be the best remedy in these circumstances, no Ontario privacy legislation exists upon which to base such a claim. Indeed, some years ago Mr. Justice Krever recommended that a statutory right be created permitting a patient to maintain a civil action for damages in cases of breach of medical confidentiality: Ontario, *Report of the Commission of Inquiry into the Confidentiality of Health Information* (1980) (Commissioner: Mr. Justice H. Krever), Vol. 1, at 15, 530-31. However, breach of a statutory duty may be *evidence* of negligence: *Her Majesty the Queen v. Saskatchewan Wheat Pool*, [1983] 1 S.C.R. 205, at 227-28, 143 D.L.R. (3d) 9, at 25.

[57] O.Reg. 490/85, s. 1(1); see discussion, *infra*, this ch., sec. 3(b).

[58] *Ibid.*, s. 1(2).

3. PROBLEMS WITH ONTARIO'S POLICIES

(a) INTRODUCTION

Public health policies ought to protect the health of the community with as few restrictions on the rights of individuals as possible without imposing undue costs on the public health.[59]

Private rights have been defined as the right of individuals to order their own activities without undue or unnecessary state interference.[60] Similarly, privacy has been described as the notion that all information about a person is in a fundamental way her own to communicate or retain for herself.[61] The notion of privacy is based upon a belief in the dignity and integrity of the individual.[62] Claims to privacy must be balanced against other societal needs, such as protection of the public health. As Mr. Justice LaForest of the Supreme Court of Canada has stated,[63] "Invasions of privacy must be prevented, and where privacy is outweighed by other societal claims, there must be clear rules setting forth the conditions in which it can be violated."

The first step in an ethical evaluation of a particular policy is a definition of the public good at issue and a determination of the value society places on the objective of the policy.[64] Second, the measure must succeed in furthering the objective.[65] And, even if the measure does so, if it infringes a private right it must be the least invasive and least restrictive reasonably available alternative that is likely to achieve the justified aim sought.[66]

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[59] Gostin, Curran, and Clark, "The Case against Compulsory Casefinding in Controlling AIDS – Testing, Screening and Reporting" (1986), 12 Am. J. L. & Med. 7, at 24.

[60] Krever and Geller, "Private Right and Public Good: The Dilemma in Legislation", in Bayefsky (ed.), *Legal Theory Meets Legal Practice* (1988), 319, at 319.

[61] *R. v. Dyment*, [1988] 2 S.C.R. 417, at 427, 55 D.L.R. (4th) 503, at 513 (subsequent references are to [1988] 2 S.C.R.).

[62] *Ibid.* LaForest J. went on to say this, at 429-30:

> In modern society, especially, retention of information about oneself is extremely important. We may, for one reason or another, wish or be compelled to reveal such information, but situations abound where the reasonable expectations of the individual that the information shall remain confidential to the persons to whom, and restricted to the purposes for which it is divulged, must be protected.

[63] *Ibid.*, at 430.

[64] Krever and Geller, *supra*, note 60, at 319.

[65] *Ibid.*

[66] Somerville and Gilmore, *Human Immunodeficiency Virus Antibody Testing in Canada*, report submitted to and approved by the National Advisory Committee on AIDS (January 6, 1988), at 11. This language is somewhat similar to a s. 1 review procedure under the

If we are to apply this framework to an evaluation of Ontario's programs of compulsory nominal reporting and contact tracing, it must be established first that the policies have a justifiable public health purpose and, second, that they further the attainment of that purpose without unduly encroaching upon the private rights of HIV-infected persons. The public health objective of nominal reporting and state-supervised contact tracing is the protection of public health and the prevention of the spread of disease. This goal is clearly of great social importance. More difficult to answer, however, is the question whether the policies actually further this objective and whether they are the least restrictive, least invasive alternative means of doing so.

(b) COMPULSORY NOMINAL REPORTING

Surveillance – the systematic collection of data concerning each case – is a cornerstone of the public health response to an outbreak of disease.[67] But does the surveillance of HIV infection through compulsory nominal reporting best achieve the goal of preventing the spread of the infection and protect the public health without unduly compromising patients' individual privacy? A number of rationales have been offered in support of compulsory nominal reporting. First, the reporting of all HIV infection cases is said to broaden the province's information base about the prevalence of the infection.[68] This in turn facilitates the planning of future health care requirements and the identification of high-risk demographic areas so that public health education efforts and programs can be implemented where they are most needed.[69] The information obtained from reporting may also contribute to the development of effective treatments or other preventive measures.[70] Reporting is said to facilitate the counselling, and where appropriate the

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Canadian Charter of Rights and Freedoms, being Part I of the *Constitution Act, 1982*, which is itself Schedule B of the Canada Act, 1982, c. 11 (U.K.) (subsequently referred to as the "Charter"). It has been suggested that Ontario's policies of compulsory nominal reporting and contact tracing may violate certain guarantees in the Charter, in particular s. 15, which provides that "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination...based on...physical disability." See, generally, Flanagan, *supra*, note 25, at 560-602. In his seminal article, Professor Flanagan proposed a constitutional argument challenging Ontario's compulsory nominal reporting requirements. Such an argument is quite complex and lengthy, however, and is beyond the scope of this chapter.

[67] Whyte *et al.*, "An Ethical Dilemma: Public Safety or Personal Privacy in Reporting HIV Infection" (1990), 79 J. Med. A. Ga. 847, at 847.

[68] Washington, D.C., Institute of Medicine, *Confronting AIDS: Update 1988* (1988), at 82 (hereinafter referred to as "*Confronting AIDS: Update 1988*").

[69] Hodgson, *supra*, note 12, at 63.

[70] *Ibid.*

treatment, of infected individuals. In addition, nominal reporting is said to be necessary to maintain a state-supervised contact-tracing process.

However, for determining seroprevalence rates, properly defined epidemiological research studies are more useful than an ad hoc collection of cases.[71] Nominal reporting does not significantly contribute to the usefulness of information for epidemiological purposes.[72] Similarly, the counselling and treatment of HIV-infected patients do not depend on compulsory nominal reporting.[73] In fact, nominal reporting may have a chilling effect on the willingness of persons to volunteer for testing, owing to their concern that their names will be reported to the government.[74] They may fear unwarranted disclosure, which could result in discrimination and an invasion of their privacy.[75] Increasing evidence shows that strict confidentiality and anonymous testing encourages people who are at high risk to learn their antibody status, while nominal reporting has the opposite effect.[76]

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[71] *Confronting AIDS: Update 1988*, *supra*, note 68, at 83.

[72] Royal Society of Canada, *AIDS: A Perspective for Canadians (Summary of Report and Recommendations)* (1988), at 11.

[73] *Infra*, this ch., sec. 4, wherein alternatives to compulsory nominal reporting are described.

[74] Ontario, Ministry of Health, *Consultation on the Implementation of a Comprehensive System of Anonymous, Non-nominal and Nominal Testing for HIV in Ontario* (May, 1991), at 3 (hereinafter referred to as the "Consultation Paper").

[75] *Ibid.* The Ontario Privacy Commissioner has commented that compulsory nominal reporting allows laboratory technicians and government authorities, as well as the patient's physician, to learn the patient's test result, along with their identity and other personal information. The Commissioner stated that "[s]uch wide dissemination and disclosure of highly sensitive personal information creates a considerable risk of unwarranted invasion of privacy": Ontario Privacy Commissioner's Report, *supra*, note 1, at 20.

[76] Kegeles *et al.*, *supra*, note 11, at 585; Kegeles *et al.*, "Mandatory Reporting of HIV Testing Would Deter Men from Being Tested", letter to editor (1989), 261 J.A.M.A. 1275. See, also, Fehrs *et al.*, "Trial of Anonymous versus Confidential Human Immunodeficiency Virus Testing" (August, 1988), 2 Lancet 379. In this study, clients were offered the option of either anonymous or "confidential" (using names) services. The availability of the anonymous option increased overall demand for testing by 50 percent and drew gay men who previously had not sought services under a confidential testing system. See, also, Johnson, Sy, and Jackson, "The Impact of Mandatory Reporting of HIV Seropositive Persons in South Carolina" (1988), presented at the IV International Conference on AIDS, Stockholm, Sweden (June, 1988). The study dealt with attendance changes at an HIV test site which required the name and address of HIV-infected persons to be reported to the state health department. Results indicated that the rate of monthly attendance by men reporting homosexual activity decreased by 51 percent. Attendance by persons with HIV antibody positive results decreased by 43 percent. Blood transfusion recipients and persons reporting no known risk contributed to an overall increase in clinic attendance of 8 percent.

No similar studies have been undertaken in Ontario. However, statistics compiled by Toronto's Hassle Free Clinic indicate a seropositive rate of 10 percent for the years 1986-1990 for all HIV tests performed at the clinic. This compares with a 4.6 percent seropositive rate for those tested province-wide: Consultation Paper, *supra*, note 74, at 2.

Bisexual men in particular are concerned about seeking testing if nominal reporting is required.[77]

Although the public health authorities' record of protecting sensitive medical information is generally good, breaches can and do occur.[78] An example of the harm resulting from breaching confidentiality in these cases is provided by the story of the Canadian schoolteacher who was tested for HIV infection without his knowledge. After his positive test result was leaked, he lost his job.[79]

Compulsory nominal reporting is not essential to the treatment or counselling of HIV-infected individuals. However, the reporting of HIV infection cases *without* personally identifying information can further the public interest in gathering important scientific information about the disease without imposing undue hardship on the patient.[80] In fact, the ultimate result of compulsory nominal reporting may be to discourage those at highest risk from testing—a cost that defeats the policy's public health purpose and clearly outweighs its potential benefits.[81]

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[77] Kegeles *et al.*, *supra*, note 11, at 585. See, also, Ontario, Ministry of Health, *AIDS Communications Research* (April 27, 1990), a study conducted in part to explore "the current attitudes and behaviours of bisexual men with respect to protecting their partners". At 13 of this report the significance of anonymous testing to the issue of encouraging at risk individuals to voluntarily determine their own HIV status is discussed:

> A real issue for these [bisexual] men was the fear that their going for a test would publicly expose their bisexuality, to the detriment of their marriage, their social life and possibly their business dealings. Several participants revealed that they had avoided being tested solely because of the lack of anonymity. *All* participants felt very strongly that the fear of disclosure, regardless of whether the test came back positive or negative, was the single greatest barrier to being tested.

The first recommendation on the list at 19 of the Ministry's conclusions and recommendations is this: "Anonymous testing for AIDS is a must."

[78] One Toronto primary care physician stated he learned the identity of two persons with HIV infection who were not his patients through the error of public health officials: Mickleburgh, "Refusal to Start Anonymous Testing Decried", *The Globe and Mail*, Toronto (October 15, 1990) A7.

[79] Royal Society of Canada, *supra*, note 72, at 10.

[80] Hodgson, *supra*, note 12, at 65.

[81] *Confronting AIDS: Update 1988*, *supra*, note 68, at 83; *supra*, note 76.

(c) STATE-SUPERVISED CONTACT TRACING

Historically, contact tracing has been used in North America as a public health tool for curtailing the spread of infectious disease.[82] The main goal of contact-tracing programs in respect of sexually transmitted diseases has been to search for past and present sexual partners of the infected individual to facilitate their treatment and cure. There is no cure for HIV infection; however, treatment with AZT and other drugs has been shown to slow the progress of the disease.[83] While medical intervention is becoming more important, the major goal of contact tracing in HIV infection cases is still to inform partners that they may be at risk of infection. Those contacts can then be offered testing and encouraged to engage in risk-reducing behaviour to contain or prevent the further spread of infection.

Because the influencing of behaviour through education is a major public health objective, contact tracing can be useful. The process targets individuals who are unaware that they are at risk, or who may not have changed their high-risk behaviour the despite HIV infection education programs directed towards the general public.[84] Educative counselling programs aimed at those individuals may prove effective in encouraging behaviour modification and reducing high-risk behaviour in some groups.[85]

Contact-tracing efforts may therefore be of greatest value when they are directed at those who might otherwise be unaware they had risked infection.[86] But contact tracing is only marginally effective in reducing the spread of HIV infection.[87] Public health authorities say that it has yet to be proved that contact tracing will control the spread of the infection.[88] Because of the infection's latency period and the mobility of contacts in high-prevalence urban areas, it is unlikely that infected individuals will be able to produce information concerning the identity and whereabouts of all sexual contacts over the last five to ten years. It is even more unlikely that persons sharing needles will be able to provide their partners' names and addresses.[89] Second, as a public health control strategy, contact tracing is less effective for HIV infection than it is for diseases that have curative therapies or vaccines available to render the infected person non-infectious.[90] The chief intervention available at present to curb HIV transmission is education that teaches people to avoid risky sexual and drug-using behaviour. Until an effective therapy is found for HIV infection, it is unlikely that contact-tracing programs will identify more than a handful of the thousands of undiagnosed Canadian cases.[91] Third, contact tracing is labour-intensive and expensive.[92] If public health authorities attempted to trace all sexual and needle-sharing contacts of all HIV-infected persons in Toronto, the cost would preclude any other preventive or educative effort.[93] Public funds could be more effectively spent on education programs, especially those targeted at individuals who practise high-risk behaviour.[94] In the absence of an effective treatment, contact tracing is only a complement to risk-reduction information programs aimed at the wider community.[95] State-supervised contact-tracing programs, profoundly coercive measures, may undermine the public health strategy of encouraging individuals to determine voluntarily their antibody status and modify their behaviour; they may also undermine public trust in the confidentiality of the physician-patient relationship.[96]

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[82] Washington, D.C., Institute of Medicine, *HIV Screening of Pregnant Women and Newborns*, Hardy (ed.) (1991), at 52 (subsequently referred to as "*HIV Screening of Pregnant Women and Newborns*").

[83] *Supra*, ch. 1, sec. 5.

[84] Flanagan, *supra*, note 25, at 589.

[85] *Ibid.*

[86] *Confronting AIDS: Update 1988*, *supra*, note 68, at 82.

[87] Flanagan, *supra*, note 25, at 590.

[88] Gemmill, *supra*, note 52, at S16.

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[89] Ontario Privacy Commissioner's Report, *supra*, note 1, at 22.

[90] Berger, "AIDS and the Law: Problems with the Ontario Health Protection and Promotion Act: A Physician's Perspective", presented to the Canadian Institute for the Administration of Justice Conference on Health Care, Ethics and the Law, Toronto, Ontario, (October 10-13, 1990), at 5; Hodgson, *supra*, note 12, at 66.

[91] Flanagan, *supra*, note 25, at 590.

[92] Berger, *supra*, note 90.

[93] *Ibid.*

[94] Flanagan, *supra*, note 25, at 590. A Toronto Board of Health survey found a dramatic increase in condom use among gay men, but called for extensive education of young men who were less inclined to practice safer sex than were older men.

[95] Hodgson, *supra*, note 12, at 67.

[96] *Ibid.* See, also, Landis *et al.*, *supra*, note 52. In this recent study in which full responsibility for notifying partners was given to the patient or to public health officials, notification by public health officials was significantly more effective. Results indicated that 50 percent of the partners in the public health group were notified, whereas only 7 percent of the partners were notified in the patient group. In the patient referral group, patients were required to locate partners, give them coded cards, and to request that they attend at the health department for counselling, testing, or both within one month. In the public health referral group, patients could choose to notify some or all of their partners themselves, with public health follow-up and assistance. The study concluded that: "[a]lthough the effectiveness of notification procedures is constrained by the accuracy of the information provided by HIV-infected patients, counselors who notify the partners of an infected patient can refer them to educational, medical, and support services targeted to persons at high risk for HIV infection and may encourage the adoption of less-risky behavior": *ibid.*

While public health studies often favour some limited form of contact tracing, at the same time they emphasize the importance of anonymous testing for HIV infection.[97] In general, the studies recommend that the tracing process should not be coercive, but should encourage infected individuals to cooperate voluntarily with their personal physicians in notifying sexual or needle-sharing contacts. In a voluntary, physician-centred program the state would not maintain lists of names and addresses for the purposes of contact tracing. Systematic nominal reporting of HIV-infected individuals is not done. If patients refused to assume responsibility for notifying their partners and did not allow their physicians to do so, the physicians would nonetheless have a power, not a duty, to notify partners who are at risk of infection. At their option, physicians or patients could seek the assistance of public health officials in the notification process.

Under the existing Ontario program, however, physicians cannot reveal HIV-related personal information to anyone without a patient's consent, except in compliance with compulsory reporting requirements.[98] The confidentiality provisions of the HPPA prohibit the disclosure of personally identifying information with respect to any person about whom a physician has made a report.[99] A physician who contravenes the confidentiality provisions of the HPPA is guilty of an offence punishable upon conviction by a maximum fine of $5,000 for every day the offence continues.[100]

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[97] See, for example, Ontario Privacy Commissioner's Report, *supra*, note 1, at 21, Recommendation 1, which states:

> Anonymous testing for the presence of HIV antibodies should be available for persons who wish to be tested. The *Health Protection and Promotion Act*, or legislation intended to replace it, should not require mandatory nominal reporting of HIV-positive results. Any obligation imposed by legislation to report nominal HIV/AIDS-related personal information should be removed, and legislation enacted to permit anonymous testing for HIV antibodies.

The Report also recommended that the patient's personal physician should be responsible for partner notification and counselling. The primary objective is "to facilitate voluntary partner notification by the affected individual": *ibid.*, at 24, Recommendation 2.

The Royal Society of Canada Report, *supra*, note 72, at 13 recommended that "reporting laws be amended to provide that the reporting of HIV seropositivity and AIDS should not identify the person". Reporting laws "should be amended to allow anonymous tests". The report also recommended a limited contact tracing program by a physician when an HIV-infected person is in such a "condition as to be dangerous to others, and that [the physician's] disclosure of information about the patient is necessary to prevent the threatened danger": *ibid.*, at 11. Somerville and Gilmore, *supra*, note 66, at xvii, in a study undertaken for the National Advisory Committee on AIDS of Health and Welfare Canada, also recommended the provision of anonymous testing with physician-centred contact tracing.

In *Confronting AIDS: Update 1988*, *supra*, note 68, at 82, the U.S. Institute of Medicine and National Academy of Sciences recommended that "mandatory reporting of seropositive test results with identifiers should not be required". However, the committee did recognize that *voluntary* contact notification programs could be useful in preventing the spread of HIV infection.

[98] HPPA, ss. 39, 25, and 26.

There is no Canadian equivalent to the physician's "duty to warn" as the concept has developed in the United States.[101] The Canadian Medical

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[99] HPPA, s. 39, *supra*, note 35, and accompanying text. Physicians are also bound ethically to maintain patient confidentiality. *Supra*, this ch., sec. 2(f).

[100] HPPA, ss. 100(3), 101.

[101] U.S. courts have dealt extensively with the difficult balancing of medical confidentiality and the public interest in disclosure. See, generally, Dickens, "Legal Limits of AIDS Confidentiality" (1988), 259 J.A.M.A. 3449. In the well-known California Supreme Court decision, *Tarasoff v. The Regents of the University of California*, 551 P. 2d 334, 131 Cal. Rptr. 14 (1976) (subsequent references are to 551 P. 2d) (hereinafter referred to as "*Tarasoff*"), the defendants argued that a duty of confidentiality prevented them from warning a person who might be at risk from attack from a mental health patient. Balancing the interests of protection of confidentiality and public safety, the Court stated at 347: "[T]he public policy favoring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins." The defendant psychologist was found liable for failure to warn a third party of his patient's intention to murder her. As a result of this decision, under certain circumstances health care professionals in the United States may be liable for failure to disclose confidential patient information to those who are in foreseeable danger of serious harm from their patients: Dickens, *supra*. *Tarasoff* ended a restrictive approach to the physician's duty to warn, evidenced in earlier cases such as *Berry v. Moench*, 73 A.L.R. 2d 315, 8 Utah 2d 191 (S.C., 1958); *Simonsen v. Swenson*, 9 A.L.R. 1250 (Neb. S.C., 1920); and *Hofman v. Blackmon*, 241 S.O. 2d 752 (Fla. 4th Dist., C.A., 1970). While establishing the psychotherapist's duty in such cases, *Tarasoff* failed to define the criteria limiting such duty. Originally, its application was limited to situations concerning a threat of violence that involved a specific and determined action: see, for example, *Thompson v. County of Alameda*, 614 P. 2d 728, 167 Cal. Rptr. 70 (S.C. in Bank., 1980); rehearing den. August 21, 1980. Subsequently, U.S. courts extended the *Tarasoff* principle to impose a more onerous obligation on physicians. See *Lipari v. Sears, Roebuck & Co.*, 497 F. Supp. 185 (1980) (a therapist's duty to warn arises when he knows or should have known that a patient's propensities present an unreasonable risk of harm to others – including those not specified by the patient); *Davis v. Lhim*, 335 N.W. 2d 481 (Mich. App., 1983); rehearing den. May 24, 1983 (a psychologist owes a duty of reasonable care to persons who are readily identified as foreseeably endangered by his patient's violent propensities); *Jablonski v. United States of America*, 712 F. 2d 391 (U.S.C.A. 9th Cir., 1983) (liability may be imposed on a therapist for failure to protect a potential victim even though the mentally ill patient made no actual threats against a particular individual); *Hedlund v. Superior Court of Orange County*, 194 Cal. 3d 805 (Cal. S.C., 1983); rehearing den. December 15, 1983) (a psychotherapist's duty to warn third parties of a patient's violent propensities includes persons other than just the intended foreseeable victims, and therefore bystanders); *Petersen v. State of Washington*, 671 P. 2d 230, 100 Wash. 2d 421 (S.C., 1983) (a psychiatrist has a duty to take reasonable precautions to protect foreseeable [though unidentifiable] victims of the patient's drug-related mental problems); *Mavroudlis v. Superior Court of the State of California for the County of San Mateo*, 102 Cal. App. 3d 594, 162 Cal. Rptr. 724 (C.A. 1st Dist., Div. 3, 1980); rehearing den. March 27, 1980) (it is not necessary for a prediction of violence to be made towards a particular person before a psychiatrist's duty to warn or to take precautions arises). As noted, the precise ambit of

Association has stated that the warning of partners at risk of HIV infection may not be unethical, and indeed may be indicated in certain circumstances.[102] However, the warning of partners without the patient's consent may constitute professional misconduct,[103] and may render the physician liable for breach of medical confidentiality.[104]

The lack of clarity in the existing law leaves physicians uncertain about their duties to their patients and to third parties when patients are unwilling to inform partners at significant risk and refuse to permit the physician to do so.[105] New measures are needed to replace Ontario's programs of compulsory nominal reporting and state-supervised contact tracing; any new policy must recognize the physician's central role in the counselling and treatment of HIV-infected patients.[106] Clear rules will help physicians balance the interests of patient confidentiality and the public health, and foster confidence in the physician-patient relationship.

4. ALTERNATIVES TO ONTARIO'S POLICIES

(a) NON-COMPLIANCE WITH COMPULSORY NOMINAL REPORTING

Faced with this confusion, some Ontario physicians did not comply with the compulsory nominal reporting provisions of the HPPA.[107] Those

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Tarasoff remains uncertain. It is unclear whether or not the principle applies directly in the case of HIV infection. All the above cases concerned patients afflicted with either a mental disorder or a communicable disease. It is arguable that such cases are distinguishable from situations involving AIDS and HIV infection.

It has also been suggested that physicians may be under a duty to warn partners of HIV-infected patients: Dickens, *supra*, at 3450; Gostin and Curran, "Aids Screening, Confidentiality and Duty to Warn" (1987), 77 Am. J. Pub. Health 361, at 364; Talbot, "The Conflict Between a Doctor's Duty to Warn a Patient's Sexual Partner That the Patient Has AIDS and a Doctor's Duty to Maintain Patient Confidentiality" (1988), 45 Wash. & Lee L. Rev. 355, at 370 *et seq.*; Flanagan, *supra*, note 25, at 599.

[102] Canadian Medical Association, *supra*, note 5, at 64B.

[103] Reg. 448, s. 27(22).

[104] See *supra*, note 56.

[105] Casswell, *supra*, note 25, at 246, states: "[W]hat little relevant case authority there is provides no clear guidance whether a physician owes a duty to warn a partner who may be at risk of HIV infection by his or her patient." See, also, Flanagan, *supra*, note 25, at 599; Levine, "Contact Tracing for HIV Infection: A Plea for Privacy" (1988), 20 Colum. Hum. Rts. L. Rev. 157.

[106] Any new policy must also provide for adequate compensation to physicians for the intensive counselling required by HIV-infected patients and their partners.

[107] HPPA, ss. 25, 26.

physicians used alternative testing procedures called "anonymous testing" and "non-nominal testing."[108] Both procedures are described below.

(i) Anonymous Testing

"Anonymous testing" as defined by the Ministry of Health[109] means a testing procedure whereby HIV antibody test results can be linked to the person being tested by a code known only to the patient. Neither the physician ordering the test nor anyone else knows the identity of the patient. The clinic physicians associated with anonymous testing were in violation of the HPPA's strict nominal reporting provisions,[110] but they have yet to be challenged by the Ministry of Health.

One Ontario clinic[111] has offered anonymous testing to its patients since November, 1985. At the clinic, appointments are required for all anonymous tests; only the patient's first name is used. An untraceable code is assigned to each patient and is used on the Ministry of Health test requisition form, the patient's blood tube, and the clinic intake file. All tests are preceded by a counselling session.[112] Patients must return to the clinic personally to obtain test results. At that time, they receive further educative counselling.[113] All positive test results are reported to the Ministry of Health, but only epidemiologically significant information, not personally identifying information, is included with the report.

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[108] Consultation Paper, *supra*, note 74, at 1 states that "non-nominal testing" means that "[r]esults can be linked to the person being tested by a code known only by the patient and the physician"; and "anonymous testing" means "[r]esults can be linked to the person being tested by a code known only to the patient. Neither the physician ordering the test nor anyone else knows the identity of the person being tested".

[109] *Ibid.*, at 1.

[110] HPPA, ss. 25, 26. As of January 1, 1992, an amendment to O. Reg. 490/85 by O.Reg. 749/91 permits an exemption from the reporting requirements pursuant to s. 26 of the HPPA for patients who have received counselling about the prevention of HIV transmission prior to the test, and whose tests are performed in one of the clinics specified in the regulation.

[111] Toronto's Hassle Free Clinic, a community-based medical clinic that also includes treatment of sexually transmitted diseases in its services to the public.

[112] At the counselling session, prior to testing, the following information is provided: an explanation about behaviour known to pose risks for transmission and contraction of HIV; a discussion of the patient's personal risk of infection and reasons for wanting to be tested; information about safer sex and other preventative measures; information about the test, including its purpose and the meaning of positive, negative and indeterminate test results; a discussion about reactions to the possibility of a positive result; information about informing partners; information concerning available social and medical support systems; and information about clinic testing procedures, including an explanation of anonymous testing procedures and the need to return to the clinic personally to obtain test results: personal conversation with Robert Trow, Counsellor, Hassle Free Clinic (June 12, 1991).

Many of the arguments for and against anonymous testing are similar to those discussed earlier in the sections on compulsory nominal reporting and contact tracing, and will not be repeated here. In essence, as the Ministry of Health has indicated recently,[114] anonymous testing is seen as a testing procedure that maximizes the number of persons who will come forward for testing and counselling, particularly those who are at the highest risk of infection.[115] Maximizing the testing and counselling of such persons ensures that more HIV-infected individuals will make use of their treatment options when it is most beneficial to do so – before symptoms develop.

The experience of Ontario's only anonymous testing site suggests that the majority of patients who test anonymously do return to learn their test results.[116] The problem of patients' failure to return for test results and post-test counselling is not restricted to anonymous testing programs. A study conducted in Oregon, which offered clients the option of anonymous or nominal HIV testing, found that 94 percent of clients who received pre-test counselling and testing returned for their test results and post-test counselling. This proportion was almost identical for both the anonymous and the nominal testing groups.[117] Thus, while the concern is legitimate, the problem is not exclusive to the provision of anonymous testing services. One way to encourage patients to return is to ensure that pre-test education and counselling is as comprehensive as possible, and emphasizes the need to inform partners. The concern most frequently voiced in relation to anonymous testing involves contact tracing. Contact tracing is entirely voluntary when an individual tests anonymously. Anonymous testing by its nature does not permit the identification of the HIV-infected individual, and health care workers are unable to reach unsuspecting partners who may be at risk.

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[113] Post-test counselling includes the following: information regarding behaviour change to prevent transmission or contraction of HIV infection; appropriate referrals for coping with the emotional consequences of testing positive; appropriate medical referrals for treatment and medical intervention; discussion about the need to inform partners; and an offer to assist the patient in this regard: *ibid.*

[114] The Minister of Health stated that the availability of accessible anonymous HIV testing services will encourage more people to come forward for testing, enabling them to take advantage of appropriate medical and social services: Consultation Paper, *supra*, note 74, at 1.

[115] *Supra*, note 76. Statistics show that approximately 30 percent of HIV tests are ordered anonymously or non-nominally, while 70 percent are ordered using the patient's name. However, data indicate that approximately 10 percent of the tests done anonymously by the Hassle Free Clinic are HIV positive – a much higher rate than the 4.6 percent of positive tests performed nominally or non-nominally: Consultation Paper, *supra*, note 74, at 2. "These numbers suggest that there is a high demand for anonymous testing among people at high risk": *ibid.*

[116] Toronto's Hassle Free Clinic's statistics indicate that during the year 1990, 90 percent of clients testing positive returned to the clinic for test results and post-test counselling: personal conversation with Robert Trow, *supra*, note 112.

[117] Fehrs *et al.*, *supra*, note 76, at 381. The study concluded that the availability of anonymous testing services increased demand for HIV testing by 50 percent overall and by 125 percent among gay men.

(ii) Non-Nominal Testing

"Non-nominal testing" as defined by the Ministry of Health means that HIV test results can be linked to the patient by a code known only to the patient and the testing physician.[118] Non-nominal testing developed as an alternative to compulsory nominal reporting because some physicians believed many high-risk individuals would refuse to come forward for testing and counselling if their names were reported to public health authorities.[119] The physicians – generally Toronto primary care physicians, who treat most of the province's HIV-infected patients – ordered tests using codes.[120] No personally identifying information was included on the test requisition form. It is important to note that the physicians still reported positive test results to public health authorities, including important epidemiological and demographic information. However, there was no systematic reporting of personally identifying patient information. Despite the refusal of the physicians who practised non-nominal testing to comply with the HPPA's strict reporting requirements, the Ministry of Health only rarely challenged the practice.

Pre- and post-test counselling is, of course, an important part of the non-nominal testing procedure, as it is with nominal testing. Non-nominal testing thus facilitates the public health goal of counselling and treatment for HIV-infected patients. It provides for collection of important epidemiological data as well as partner notification, and intrudes less on the patient's privacy than nominal reporting. In this respect non-nominal testing makes the patient the primary focus of the testing procedure, and enhances trust in the confidentiality of the physician-patient relationship by limiting the potential for disclosure of potentially harmful information.

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[118] Consultation Paper, *supra*, note 74, at 1.

[119] Berger, *supra*, note 90, at 6.

[120] *Ibid.*

(b) THE MINISTRY OF HEALTH REFORMS

(i) The Provision of Anonymous Testing Services

In April, 1991, the Ministry of Health announced major reforms to Ontario's public health policy concerning HIV infection.[121] The first part of the policy involves the provision of anonymous testing services,[122] implemented by an amendment to the regulation under the HPPA.[123]

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[121] Ontario, statement by Evelyn Gigantes, Minister of Health, to the Legislature re extending AIDS services, Queen's Park (April 15, 1991) (hereinafter referred to as the "Minister's Statement").

[122] Wong, "Anonymous AIDS Tests Get Funding in Ontario", *The Toronto Star* (October 7, 1991) A1.

[123] O.Reg. 490/85, as am. by O.Reg. 749/91, which provides:

> 5a.-(1) In this section,
>
> "AIDS" means Acquired Immune Deficiency Syndrome; ("sida")
>
> "HIV" means Human Immunodeficiency Virus. ("VIH")
>
> (2) A physician who provides professional services to a patient in a clinic set out in subsection (4) and who is required to report under section 26 of the Act following a test to determine if the patient is infected with an agent of AIDS is exempt from reporting the patient's name and address if, before the test was ordered, the patient received counselling about preventing the transmission of HIV infection.
>
> (3) The operator of a laboratory is exempt from reporting, under section 29 of the Act, the name and address of a person who has tested positive for an agent of AIDS if the test is in relation to professional services provided at a clinic described in subsection (4).
>
> (4) The following are the clinics referred to in subsections (2) and (3):
>
> 1. Anishnawbe Health Toronto, 225 Queen Street East, Toronto.
> 2. Barrie STD Clinic, 370 Dunlop Street, Barrie.
> 3. Birth Control & STD Information Centre, 2828 Bathurst Street, North York.
> 4. Brampton-Caledon STD Clinic, 180B Sandalwood Parkway East, Brampton.
> 5. Centretown Community Health Centre, 340 MacLaren Street, Ottawa.
> 6. Hassle Free Clinic, 556 Church Street, Toronto.
> 7. Mississauga East STD Clinic, 3038 Hurontario Street, Mississauga.
> 8. Mississauga West STD Clinic, 2227 South Millway, Mississauga.
> 9. Sandy Hill Community Health Centre, 24 Selkirk Avenue, Vanier.
> 10. SITE, 480A Somerset Street West, Ottawa.

Physicians performing anonymous testing will continue to collect and forward to the medical officer of health important statistical information on age, sex, and risk factors for all positive test results.[124] However, no names or other personally identifying information will be required of persons who choose to be tested anonymously. Pre- and post-test counselling will be an integral part of the anonymous testing procedure.[125] The Ministry hopes that the availability of accessible, anonymous HIV testing services will encourage more people to voluntarily learn their antibody status and obtain social and medical assistance.[126] We believe that the provision of province-wide anonymous HIV antibody-testing services is an important part of a comprehensive public health strategy to help reduce the spread of HIV infection in Ontario.

(ii) The Provision of Non-Nominal Testing Services

The second part of the reform policy attempts to amend Ontario's compulsory nominal reporting requirements to provide for non-nominal testing under the HPPA. The proposed amendment relates specifically to the implementation of non-nominal testing services. The Ministry of Health acknowledges the concern of many individuals who fear that "their names will be reported to the public health system".[127] The Ministry has said that the proposed changes to the reporting requirements will help to address the fear of discrimination and the fear of loss of privacy that many people associate with HIV antibody testing under the province's current public health model.[128]

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11. Somerset West Community Health Centre, 755 Somerset Street West, Ottawa.
12. STD Clinic, 237 Barton Street East, Hamilton.
13. STD Clinic, 250 Besserer Street, Ottawa.

2. This Regulation comes into force on the 1st day of January, 1992.

[124] This is currently standard practice at Toronto's Hassle Free Clinic: personal conversation with Robert Trow, *supra*, note 112.

[125] Consultation Paper, *supra*, note 74, at 1.

[126] *Ibid.*

[127] *Ibid.*, at 3.

[128] *Ibid.*

The new policy would amend the regulation under the HPPA.[129] Compulsory nominal reporting would remain under the plan;[130] however, non-nominal and anonymous testing would be added as testing options. As a standard of practice, physicians would be required to inform patients of the implications and procedures involved with all three types of HIV antibody testing.[131] The proposed amendment, which pertains to the non-nominal testing option, would still require the collection of important statistical and demographic information on all test results reported to the Ministry of Health. Pre- and post-test counselling would be part of the non-nominal testing procedure.

The proposed amendment attempts to institute non-nominal testing in the following way.[132] Physicians would be exempt from identifying an HIV-infected patient by name and address under section 26 of the HPPA to the medical officer of health for sixty days after forming the opinion that a patient is or may be infected with an agent of AIDS. After sixty days the physician is exempt from reporting the patient's name and address if the following conditions are met: (1) the medical officer of health is satisfied that all identifiable persons who may have been exposed to infection by the patient through sexual intercourse, sharing needles, or "any other way" have been notified and offered appropriate counselling; (2) the medical officer of health is satisfied that the patient has received adequate counselling about preventing transmission of HIV infection; and (3) the medical officer of health has no reason to believe the patient is likely to expose others to infection.[133]

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[129] O.Reg. 490/85.

[130] Consultation Paper, *supra*, note 74, at 1.

[131] *Ibid.*

[132] The proposed amendment to O.Reg. 490/85 provides in full:

> A physician who forms an opinion that a patient is or may be infected with an agent of AIDS is exempt from reporting the patient's name and address under section 26 of the Act to a medical officer of health for sixty days following the time the physician formed the opinion.
>
> After the sixty days, the physician is exempt from reporting the patient's name and address under section 26 of the Act if the medical officer of health, based on information received from the patient's physician:
>
> - has no reason to believe the patient is likely to expose others to risk of infection with an agent of AIDS;
> - is satisfied that all identifiable persons who may have been exposed to the risk of infection with an agent of AIDS by the patient through sexual intercourse, the sharing of needles used for injections or any other way have been notified of the risk of infection and of the availability of counselling about preventing the transmission of HIV infection; and
> - is satisfied that the patient has received counselling about preventing the transmission of HIV infection.

Consultation Paper, *supra*, note 74, at 5.

While the goal of the proposed amendment is to enhance the confidentiality of HIV antibody testing by protecting the privacy of the infected patient,[134] the proposal is in fact another reporting statute. Significantly, the amendment does not eliminate nominal reporting. It simply sets out new conditions that trigger compulsory nominal reporting when the patient chooses the non-nominal testing procedure.

The first problem the proposal raises is that physicians may revert to nominal reporting as the most prudent way of acting in the absence of protection against a potential claim for failure to warn a third party. Physicians are not given immunity from such liability. Second, the language of the proposal is unclear. Precisely what information, for example, will give a medical officer of health "no reason to believe" that a patient may or may not be "likely to expose others to risk of infection"? Similarly, how are physicians to know what information will satisfy public health authorities across the province that "all identifiable persons who may have been exposed to the risk of infection...by the patient through sexual intercourse, the sharing of needles used for injections or any other way have been notified"? For that matter, how are medical officers of health to know, without more, the kind of assurances doctors should give them before nominal reporting is required? Physicians concerned about the lack of precision in the language may simply choose to report nominally rather than deal with the uncertainties of the amendment. Third, while the proposal attempts to exempt physicians' nominal reporting in at least some cases, the *system* of compulsory nominal reporting remains virtually intact. School principals, for instance, will still be required under the HPPA to report nominally HIV-infected students to the medical officer of health.[135] Hospital administrators will still be required to report the identity of all in-patients and out-patients who are HIV-infected.[136] Government laboratories, which perform all HIV antibody tests, will still be required to report the identity of persons testing positive to public health authorities.[137] And, while the proposal may exempt nominal reporting by physicians under section 26 of the HPPA, physicians will still be required to report the names of infected patients under the provisions in section 25.[138] Finally, the proposal does not provide clear direction to physicians who need to know in what circumstances disclosure of HIV-related personal information is warranted. The provision of anonymous testing is an important part of an overall strategy in the fight against HIV infection. However, the proposed amendment to the regulation respecting non-nominal testing fails to address the underlying problems associated with Ontario's system of compulsory nominal reporting.

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[133] *Ibid.*

[134] *Ibid.*, at 3.

[135] HPPA, s. 28.

[136] HPPA, s. 27.

[137] HPPA, s. 29, except where the test has been performed "in relation to professional services provided at a clinic" designated in the regulation: O.Reg. 490/85, as am. by O.Reg. 749/91.

(c) A COMPREHENSIVE APPROACH

Recognizing the sensitivity of HIV-related personal information and the potential for its misuse, a number of jurisdictions have enacted HIV-specific legislation that closely governs its disclosure.[139] In particular, the states of California and New York have enacted omnibus HIV legislation regulating access to and disclosure of health care information about HIV infection.[140] Legislative measures may be the best vehicle to deal effectively and comprehensively with a broad range of HIV-specific issues. Those issues include rules requiring voluntary, specific, informed consent for all HIV-related testing, including the circumstances in which mandatory or compulsory testing may be permitted, the protection of confidentiality of HIV-related information, and the disclosure of that information where warranted. Appropriate remedies for violation of the legislative scheme, such as fines or civil causes of action, could be included in the legislation.

The New York statute is a good example of comprehensive legislation which recognizes that strong confidentiality protections can limit the risk of discrimination and the potential harm to an individual's interest in privacy caused by unauthorized disclosure.[141] While the HPPA is effectively silent

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[138] It is also arguable that the proposed amendment may be *ultra vires*. See Part VIII of the HPPA, concerning regulation-making powers under the Act.

[139] Many U.S. states have enacted HIV-specific legislation which attempts to protect the confidentiality of HIV-related personal information: Dickens, *supra*, note 13, at 100.

[140] California Health & Safety Code, §199.22 as en. by Stats. 1985, c. 22, §1; amended by Stats. 1987, c. 1391, §2; Stats. 1988, c. 1581, §5; Stats. 1988, c. 1582, §2 (West Supp. 1990); New York HIV and AIDS Related Information Law, §§2780-2787, as en. by L. 1988, c. 584, §2 (McKinney Supp. 1989) (hereinafter referred to as the "New York Act").

[141] New York Act, Statement of Legislative Intent, L. 1988, c. 584, §1. See Memorandum in Support, N.Y. Bill s. 9265-A, A. 9765-A (July 15, 1988), at 3-4:

> In its final report, the President's Commission on the HIV Epidemic noted that confidentiality protections are the cornerstone of any public health strategy to control the spread of AIDS, because all available strategies rely on the voluntary cooperation

as to when disclosure of HIV-related information may be justified, the New York Act governs *all* disclosure of HIV-related information. By providing clear and certain rules for the disclosure of such information, the New York statute contemplates the expansion of voluntary HIV testing with the express purpose of encouraging those at risk to come forward. The statement of legislative intent provides in part as follows:[142]

> The legislature recognizes that maximum confidentiality protection for information related to human immunodeficiency virus (HIV) infection and acquired immune deficiency syndrome (AIDS) is an essential public health measure. In order to retain the full trust and confidence of persons at risk, the state has an interest both in assuring that HIV related information is not improperly disclosed and in having clear and certain rules for the disclosure of such information. By providing additional protection of the confidentiality of HIV related information, the legislature intends to encourage the expansion of voluntary confidential testing for the human immunodeficiency virus (HIV) so that individuals may come forward, learn their health status, make decisions regarding the appropriate treatment, and change the behavior that puts them and others at risk of infection.

In contrast to Ontario, the New York legislation does not require compulsory nominal reporting of HIV infection, and no state records of HIV-infected individuals are maintained. Informed consent to HIV testing under the New York Act includes an explanation that the test is voluntary, that consent may be withdrawn at any time, and that anonymous testing is available.[143] The legislation governs the release of all HIV-related

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> of those at risk. Fear of breaches of confidentiality may discourage those at risk from using available health and social services to learn their HIV status and be counselled on how to prevent future infection or transmission of the virus. This [legislation] reinforces and expands the confidential relationship between individuals at risk of HIV infection and providers of health or social services who are likely to obtain such information in the course of their work. In addition to the Commission, the Institute of Medicine of the National Academy of Sciences, the Association of State and Territorial Health Officials, and the American Medical Association have all recommended the adoption of strong confidentiality protections for HIV-related information.

[142] New York Act, Statement of Legislative Intent, *supra*, note 141, s. 1.

[143] New York Act, §2781.2. According to the New York Department of Health's instructions in *A Guide to HIV Counseling and Testing* (February, 1990), at 7, physicians must discuss with patients the difference between confidential and anonymous testing at the pre-test counselling session, as follows:

> 1. Confidential: Explain that the advantage of confidential counseling and testing done in the medical setting is that necessary medical care and services can be provided or arranged. HIV counseling and testing information, including the test result, is recorded in the patient's medical record; the result is protected by state law from unauthorized disclosure. Blood specimens and test results are identified to the laboratory only by a code number, not by name.

information obtained not only by the state, but by *anyone*, thus providing effective and comprehensive confidentiality protection. Unauthorized disclosure of HIV-related information, including the fact that a person was tested for HIV, is prohibited under the New York Act.[144]

The statutory provisions governing disclosure of information are of considerable interest. Disclosure is generally permitted to health facilities where it is necessary to provide appropriate care, as required by federal or state law, to probation and correction facilities, to foster care and adoption agencies, and to insurers for the purposes of third-party payments.[145] Disclosure is also permitted, of course, where it is authorized by the patient.[146] Generally speaking, where disclosure is authorized, the statute prohibits redisclosure without the patient's specific written consent.[147] Severe penalties are imposed for violation of the informed consent and confidentiality provisions.[148] The New York legislation also provides a complete code for court authorization of disclosure of confidential HIV-related information.[149] Generally speaking, a court may grant an order for disclosure of HIV-related information upon an application showing: a compelling need for disclosure for the adjudication of a criminal or civil proceeding; a clear and imminent danger to an individual whose life or health may unknowingly be at signficant risk as a result of contact with the person about whom the information pertains; upon application of a public

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2. Anonymous: Anonymous counseling and testing is available through the New York State Department of Health's HIV Counseling and Testing Program, some public sexually transmitted disease clinics and the New York City Department of Health. No personally identifying information is asked at any time. Records and blood specimens are identified by code numbers.

[144] New York Act, §2782.5.

[145] *Ibid.*, §2782.

[146] *Ibid.*

[147] All disclosures of confidential HIV-related information, except disclosures made to the patient, or to individuals authorized to consent to care for the patient, or to known contacts as permitted by law, must be accompanied or followed by a statement in writing that includes the following language, as contained in the New York Act, §2782.5:

> This information has been disclosed to you from confidential records which are protected by state law. State law prohibits you from making any further disclosure of this information without the specific written consent of the person to whom it pertains, or as otherwise permitted by law. Any unauthorized further disclosure in violation of state law may result in a fine or jail sentence or both. A general authorization for the release of medical or other information is not sufficient authorization for further disclosure.

[148] *Ibid.*, §2783.

[149] *Ibid.*, §2785.

health officer, a clear and imminent danger to the public health; or, that the applicant is lawfully entitled to the disclosure.[150]

The New York Act places the physician at the centre of the partner-notification process. The state's policy of physician-centred contact tracing endorses voluntary partner notification to help patients cooperate with their personal physicians.[151] Alternatively, with the patient's consent, the physician can assist the patient in the notification process. Since there is a compelling need to notify unsuspecting identifiable third parties at significant risk of HIV infection, disclosure for the purposes of partner notification without the patient's consent is justified in these exceptional circumstances. The statute provides that a physician may disclose confidential HIV-related information to spouses, sex partners, or needle-sharing partners of the infected person under the following conditions:[152]

(1) the disclosure is made to a contact[153] or to a public health officer;

(2) the physician reasonably believes the disclosure is medically appropriate and there is significant risk of infection to the contact;

(3) the physician has counselled the tested person regarding the need to notify the contact and reasonably believes the person will not inform the contact;

(4) the physician has informed the tested person of the intent to make disclosure to the contact.

The New York Act also requires that physicians give the patient an opportunity to express a preference as to whether disclosure should be made by the physician directly or to a public health officer.[154] Physicians must honour the patient's preference.[155] Guidelines are also provided for disclosure to partners:[156] physicians or public health officers must provide appropriate medical advice, counselling for coping with the emotional consequences of learning the information, and behaviour modification.[157] Disclosure in these circumstances must be made in person,[158] and the disclosure of the identity of the patient or any other contact is prohibited,[159] as is the case in Ontario.

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[150] *Ibid.*, §2785.2.

[151] There are additionally two confidential public health programs available to assist patients with notifying their partners: New York Department of Health *supra*, note 143, at 37.

[152] New York Act, §2782.4(a)(1)-(4).

[153] "Contact" is defined in §2780.10 of the New York Act as "an identified spouse or sex partner of the protection individual or a person identified as having shared hypodermic needles or syringes" with the patient.

[154] New York Act, §2782.4(a)(4).

[155] *Ibid.*

[156] *Ibid.*, §2782.4(b).

In New York, physicians have a power, not a duty, to disclose HIV-related personal information to a contact in clearly defined circumstances. It is reasonable to assume that physicians will fulfil such duties. The physician's responsibility to disclose in the context of partner notification is similar to many other legal and professional responsibilities to disclose information to prevent imminent harm to others.[160] Physicians in Ontario already play a central role in the majority of cases of notification of partners of HIV-infected patients.[161] In addition, the Canadian Medical Association has stated that disclosure by physicians to a partner may be indicated when physicians are confronted with an HIV-infected patient who is unwilling to inform the person at risk.[162] Although there are severe penalties for non-compliance with the statute's confidentiality provisions,[163] physicians are immune from criminal or civil liability for the failure to disclose, or the disclosure of, confidential HIV-related information when they act in good faith and without malice.[164]

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[157] *Ibid.*

[158] Note, however, §2782.4(b) of the New York Act provides: "A physician or public health officer shall...make such disclosure in person, *except where circumstances reasonably prevent doing so*" [Emphasis added].

[159] New York Act, §2782.4(b).

[160] Physicians are required by law to report to the Ontario Ministry of Transportation and Communications, for example, all those patients with an illness that may make it hazardous for them to drive. See, generally, Sharpe, *supra*, note 56, at 184.

[161] Flanagan, *supra*, note 25, at 596; Ontario Privacy Commissioner's Report, *supra*, note 1, at 22.

[162] The Canadian Medical Association, *supra*, note 5, at 64A-B, recommends the following approach:

> The CMA advises physicians that disclosure to a spouse or current sexual partner may not be unethical and, indeed, may be indicated when physicians are confronted with an HIV-infected patient who is unwilling to inform the person at risk. Such disclosure may be justified when all of the following conditions are met: the partner is at risk of infection with HIV and has no other reasonable means of knowing of the risk; the patient has refused to inform his or her sexual partner; the patient has refused an offer of assistance by the physician to do so on the patient's behalf; and the physician has informed the patient of his or her intention to disclose the information to the partner.

[163] New York Act, §2783.1(b) states that any person who discloses confidential HIV related information in violation of §2782 shall be subject to a civil penalty of up to $5,000 for each occurrence. Any person who wilfully commits an act set out in §2783.1 is guilty of a misdemeanour: §2783.2.

In addition to the problems of confidentiality raised by contact tracing, there are a number of other contexts in which confidentiality issues arise. The New York statute deals with a number of questions of this kind including disclosure of confidential HIV-related information to health care facilities, health care providers, to foster care or adoption agencies, correction officials, and insurance companies, to name only a few.[165] Our study has focused on issues relating to mandatory testing, compulsory nominal reporting, and contact tracing, and we have not attempted to deal with the broader range of issues involving confidentiality. Accordingly, we limit ourselves to the observation that there are other related and important questions that need to be addressed if the government proceeds to develop a comprehensive legislative proposal dealing with HIV-related testing and the whole range of confidentiality issues arising therefrom. We believe that strong confidentiality protection for all HIV-related information is essential not only to prevent serious consequences that can arise from disclosure, but also to control the epidemic by encouraging people at risk to come forward, learn their antibody status, and engage in risk-reducing behaviour.

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[164] *Ibid.*, §2783.3. This section provides in full:

> 3. There shall be no criminal sanction or civil liability on the part of, and no cause of action for damages shall arise against any physician or his or her employer, or health facility or health care provider with which the physician is associated, solely on account of:
>
> (a) the failure to disclose confidential HIV related information to a contact or person authorized pursuant to law to consent to health care for a protected individual; or
>
> (b) the disclosure of confidential HIV related information to a contact or person authorized pursuant to law to consent to health care for a protected individual, when carried out in good faith and without malice, and in compliance with this article; or
>
> (c) the disclosure of confidential HIV related information to any person, agency, or officer authorized to receive such information, when carried out in good faith and without malice, and in compliance with the provisions of this article.

See, also, Memorandum in Support, *supra*, note 141, at 4:

> The proliferation of HIV-related information requires that, in addition to protections, the Legislature provide clear and certain rules for disclosure of such information. The lack of such rules has generally led to confusion regarding the sharing of HIV-related information between medical and social service professionals charged with the care and provision of services to persons with HIV infection. In addition, physicians face possible liability for warning third parties regarding their risk of infection. This legislation is designed to clarify the issue of when and to whom HIV-related information may be disclosed.

[165] New York Act, §2782.1(a)-(o).

Ontario's policy of systematic nominal reporting should be replaced with a policy of reporting only epidemiologically significant information without personally identifying the HIV-infected patient. The Commission recommends that any patient seeking an HIV-related test should be provided with the opportunity to test non-nominally or to remain anonymous and to provide voluntary, specific, and informed consent through the use of a coded system with no linking of the patient's identity to test results. A voluntary physician-centred program of partner notification should replace the current state-supervised scheme.[166] The Commission recommends that the following principles should govern partner notification: (1) patients should be encouraged to notify partners voluntarily, or to cooperate with their personal physician's attempt to do so, within a physician-centred program of partner notification; (2) physicians should be able to directly notify identifiable, unsuspecting partners of HIV-infected patients who are at risk, under clearly defined guidelines governing the disclosure of HIV-related information; (3) the option to seek the assistance of public health authorities in the notification process should be available to both physicians and patients; and (4) physicians who notify partners should be protected against the potential for liability resulting from responsibilities relating to partner notification.

One outstanding and, in the Commission's view, unresolved issue remains respecting contact tracing: should the physician or public health official ever be able to identify the infected patient to a partner? To answer the question, a number of conflicting interests must be reconciled. The privacy interest of the patient, recognized in law, and the obligation of the physician to maintain the confidentiality of HIV-related patient information,[167] weigh in favour of prohibiting disclosure of the identity of a patient in the absence of the patient's consent. Against that interest is the interest of the partner who must be provided with information that will facilitate the curbing of the spread of disease which might require, in at least in some cases, disclosure of the patient's identity. A further interest must be weighed in the balance. There is a broader social interest in maximizing the effectiveness of partner notification programs. Will a policy of strict non-disclosure of patient identity provide for more effective contact tracing, with the result that larger numbers of people will be encouraged to avoid behaviour that subjects them to the risk of acquiring an incurable and fatal illness?

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[166] Hodgson, *supra*, note 12, at 67.

[167] See *supra*, note 9.

In attempting to strike a balance amongst these competing interests, a number of policy responses are possible. Current Ontario practice is one of strict non-disclosure of patient identity.[168] At the other end of the spectrum is a policy permitting such disclosure. A middle ground is reflected in the New York statute. Although the statute generally prohibits the disclosure of patient identity, the legislation provides for court authorization for disclosure of confidential HIV-related information in circumstances where such disclosure appears necessary to avert an imminent peril to the safety of a partner.[169]

We are reasonably confident that a general policy favouring disclosure would so inhibit the process of contact tracing that its overall effect would be counter-productive. The virtue of the current Ontario practice, of course, is that it maximizes the protection of patient privacy and would appear to foster the goal of maximizing voluntary contact tracing. However, there may be situations of imminent peril to a partner, where disclosure of the patient's identity is arguably necessary, notwithstanding the possible chilling effect on the program of voluntary partner notification in a more general way. The virtue of a provision such as that contained in the New York Act is to regularize the practice of disclosure, and subject it to court supervision.

Unfortunately, we are not in possession of the information necessary to permit the making of an informed choice between these types of policy responses. We are not aware of the extent to which counsellors implementing the current non-disclosure policy feel that there is a problem that might be solved by the adoption of the New York model or some variation thereof. Nor do we have a sense of the extent to which partners are experiencing difficulties reaching appropriate conclusions about risk-avoidance behaviour under the current policy. Accordingly, we are disinclined to make a recommendation on this issue at this time. Should comprehensive HIV legislation be enacted, however, we believe that further inquiries should be made, perhaps through the Ministry of Health, to attempt to establish a body of information on which an informed choice could be based as to the appropriate policy response on this issue.

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[168] Gemmill, *supra*, note 52, at S17.

[169] *Supra*, note 149. New York Act, §2785.6 provides:

> An order authorizing disclosure of confidential HIV related information shall:
>
> (a) limit disclosure to that information which is necessary to fulfill the purpose for which the order is granted; and
>
> (b) limit disclosure to those persons whose need for the information is the basis for the order, and specifically prohibit redisclosure by such persons to any other persons, whether or not they are parties to the action; and
>
> (c) to the extent possible consistent with this section, conform to the provisions of this article; and
>
> (d) include such other measures as the court deems necessary to limit any disclosures not authorized by its order.

CHAPTER 4

SUMMARY OF RECOMMENDATIONS

The Commission makes the following recommendations:

1. No HIV-related test should be performed without first receiving the voluntary, specific, and informed consent of the patient, except where an HIV-related test is performed

    (a) in relation to the use of blood, organs, tissue, or body parts in medical research, treatment, or transplantation; or

    (b) as part of an anonymous HIV screening program for epidemiological or research purposes.

2. Any patient seeking an HIV-related test should be provided with the opportunity to test non-nominally or to remain anonymous and to provide voluntary, specific, and informed consent through the use of a coded system with no linking of the patient's identity to test results.

3. The following principles should govern partner notification:

    (a) patients should be encouraged to notify partners voluntarily, or to cooperate with their personal physician's attempt to do so, within a physician-centred program of partner notification;

    (b) physicians should be able to directly notify identifiable, unsuspecting partners of HIV-infected patients who are at risk, under clearly defined guidelines governing the disclosure of HIV-related information;

    (c) the option to seek the assistance of public health authorities in the notification process should be available to both physicians and patients;

    (d) physicians who notify partners should be protected against the potential for liability resulting from responsibilities relating to partner notification.

APPENDIX I[*]

Table 1(a) Predictive Value of a Repeatedly Reactive Screening Test for Asymptomatic HIV Infection with a Prevalence of Infection in the Population of 0.2 Percent

Test Result	Actual Condition		Totals		Predictive Value (percent)
	Infected	Not Infected	Number	Percent	
Reactive	196	998	1,194	1.2	16.4
Nonreactive	4	98,802	98,806	98.8	99.99
Totals	200	99,800	100,000	100	

Note: Assumptions—test sensitivity, 98.0 percent; test specificity, 99.0 percent.

Table 1(b) Predictive Value of a Repeatedly Reactive Screening Test for Asymptomatic HIV Infection with a Prevalence of Infection in the Population of 20 Percent

Test Result	Actual Condition		Totals		Predictive Value (percent)
	Infected	Not Infected	Number	Percent	
Reactive	19,600	800	20,400	2.04	96.1
Nonreactive	400	79,200	79,600	79.6	99.5
Totals	20,000	80,000	100,000	100	

Note: Assumptions—test sensitivity, 98.0 percent; test specificity, 99.0 percent.

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[*] Table 1(a) and 1(b) are taken from *HIV Screening of Pregnant Women and Newborns* (1991), Washington, D.C., Institute of Medicine, at 21.

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